



The right of people with **disabilities**
to live **independently** and
be **included in the community**



COMMISSIONER FOR HUMAN RIGHTS
COMMISSAIRE AUX DROITS DE L'HOMME



The right of people with disabilities to live independently and be included in the community

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- European Network Disability Federation of Ireland
- European Network on Independent Living
- European Network of (Ex-)Users and Survivors of Psychiatry
- Inclusion International
- Mental Disability Advocacy Centre
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- Centre for Disability Law and Policy, National University of Ireland, Galway
- The Open Society Foundations

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Summary

Recognizing the right to live in the community is about enabling people to live their lives to their fullest within society and access the public sphere, including “small places, close to home.”¹ It is a foundational platform for all other rights: a precondition for anyone to enjoy all their human rights is that they are within and among the community.

The right to live in the community is closely linked with fundamental rights such as personal liberty, private and family life and freedom from ill-treatment or punishment, but is captured as a distinct right in the UN Convention of the Rights of Persons with Disabilities (CRPD). The overarching objective of Article 19 of CRPD is full inclusion and participation in society. Its three key elements are: choice; individualised supports that promote inclusion and prevent isolation; and making services for the general public accessible to people with disabilities.

This right is violated when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support; when support is provided in a way that takes away people’s control from their own lives; when support is altogether withheld, thus confining a person to the margins of the family or society; or when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition.

This Issue Paper is prompted by the opportunity that the CRPD affords for promoting the right to live in the community on the one hand, and worrying trends in the implementation of this right on the other hand. Millions of people with disabilities in Council of Europe member states are denied the right to live in the community. Placement in institutions, still affecting the lives of more than a million people with disabilities across Council of Europe countries, is a pervasive violation of this right which calls for a firm commitment to deinstitutionalisation. Many more are isolated within their own communities due to inaccessibility of facilities such as schools, health care and transportation and lack of community-based support schemes.

Revealing the various ways in which this right is violated is essential to ensure that one form of exclusion and segregation, such as institutionalisation, is not replaced by another form, such as other, even if smaller, frameworks of

1. Louise Arbour, then United Nations High Commissioner for Human Rights, at the opening of the Convention on the Rights of Persons with Disabilities for signature, based on Eleanor Roosevelt, “The Great Question”, remarks delivered at the United Nations in New York on the occasion of the tenth anniversary of the adoption of the Universal Declaration of Human Rights on 27 March 1958.

congregate care. Creating an alternative in the form of support services that do not enable choice or interaction with the community – as is happening in some countries that have subscribed to a process of implementing the right to live in the community – does not amount to implementing this right either.

The Issue Paper traces the right to live in the community to its origins in the most fundamental human rights standards both within the Council of Europe and United Nations systems. It draws on Article 19 of the CRPD to identify the various forms of violation and provides guidance on community-based responses governed by choice and on achieving inclusion and participation. The paper shows the link between the right to live in the community and other rights, notably the right to equal recognition before the law (legal capacity), which is necessary to ensure an individual's choice of where and with whom to live, as opposed to such choice being exercised by a person or entity acting as the individual's guardian. This Issue Paper ends with a sample of indicators and guidance questions to help assess whether a country is transitioning from violation to implementation of the right to live in the community.

The Commissioner's recommendations

In order to ensure the effective enjoyment of the right to live in the community for people with disabilities, the Commissioner for Human Rights calls on Council of Europe member states to:

1. ratify the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol;
2. review their legislation and policy in the light of Article 19 of the UN Convention on the Rights of Persons with Disabilities, with a view to ensuring that everyone with disabilities enjoys an effective right to live independently and be included in the community, irrespective of the nature of the impairment;
3. ensure that all people with disabilities have the legal capacity to make decisions, including those affecting their right to live independently and to be included in the community, through appropriate supported decision-making if needed;²
4. adopt a no-admissions policy to prevent new placements of persons with disabilities in institutional settings;
5. set deinstitutionalisation as a goal and develop a transition plan for phasing out institutional options and replacing them with community-based services, with measurable targets, clear timetables and strategies to monitor progress;
6. allocate the necessary budgetary and other resources towards community-based supports rather than institutional placement and services, in accordance with the principle of progressive realisation;
7. ensure that the process of transition to community-based services and supports does not fall short of achieving full implementation of the right to live in the community, recognising that smaller institutions or segregated frameworks and mechanisms, such as congregate care, even when physically placed in the community, do not satisfy the conditions set in Article 19 of the UN Convention on the Rights of Persons with Disabilities;
8. develop and implement a plan for services such as personal assistance, housing, support in finding a job, life planning, and support to family, which prevent isolation within the community, and which ensure that a

2. See the Commissioner's recommendations on legal capacity, *Who gets to decide?: right to legal capacity for persons with intellectual and psychosocial disabilities*, CommDH/Issue Paper (2012)2, p. 5.

person's support needs do not compromise their full and equal participation and inclusion in society;

9. develop and implement a plan to support families who have a child with a disability to enable the child a full life within family and community and prevent isolation and institutionalisation;
10. define a statutory and enforceable individual entitlement to a level of support which is necessary to ensure one's dignity and ability to be included in the community;
11. review the nature and purpose of services offered to persons with disabilities with a view to enabling them to lead the life they prefer, by maximising their choice and control of support services and by avoiding bundling such services in a way which compromises that choice;
12. enable persons with disabilities to purchase their own supports and access housing in the general housing market;
13. critically examine the inclusiveness of community services for the general population with a view to making these services responsive to the needs of persons with disabilities;
14. ensure monitoring by independent national mechanisms of the human rights of residents of institutions until institutions are phased out, and of the human rights of people using community support services, including the quality and accessibility of community-based schemes and supports;
15. ensure that persons with disabilities and their representative organisations are involved and participate fully in planning, carrying out and monitoring the implementation of the right to live in the community.

Introduction

The right to live independently and to be included in the community stems from some of the most fundamental human rights standards, both within the Council of Europe and United Nations systems. These standards have been captured in Article 19 of the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the CRPD also provides guidance for what is included within the concept of living independently and being included in the community.

Understanding what the right to live in the community looks like when implemented, and when violated, is an essential component for the implementation of this right by member states, as well as its pursuit by all relevant stakeholders. This Issue Paper aims to draw out the guidance contained in international standards, and in particular Article 19 of the CRPD, in order to promote this understanding. It also seeks to present this guidance to those who engage in monitoring whether and how governments are implementing the right to live in the community. Monitoring entities may include governments themselves, the international disability community, local organisations of people with disabilities, and domestic, regional and international human rights organisations and mechanisms.

The right to live in the community applies to all people with disabilities. No matter how intensive the support needs, everyone, without exception, has the right and deserves to be included and provided with opportunities to participate in community life. Time and again it has been demonstrated that people who were deemed too “disabled” to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices. Programs from around the world have shown that all types of support needs can be answered, and are better answered, in community settings, which allow for expression of individuality and closer scrutiny to prevent abuse.

The right to live in the community with choices equal to others presumes a set of options for living arrangements of which members of a community avail themselves. These vary from country to country and region to region, and their violation with regard to people with disabilities takes different forms. This Issue Paper endeavours to encompass as many of these contexts as possible. It takes into account contexts that rely heavily on institutions, as well as those that do not, but suffer from an acute lack of community support services. Though some sections may be more relevant than others when applied to a specific country, this Issue Paper aims at capturing how the right to live in the community is implemented in various national contexts.

Chapter 1 of this Issue Paper presents the basic elements of the right to live in the community. It sets out the content of the core right and how a grasp of the right (or lack of it) shapes the response.

In **Chapter 2**, the Issue Paper describes the roots of the right to live in the community and its evolution in European and international law.

Chapter 3 provides more detailed guidance on the implementation of the right. It also looks at the range of ways in which the right may be violated – whether by confining people to institutions, keeping them at the outskirts of society, or segregating them within their own communities.

The **Appendix** to the Issue Paper provides a sample of indicators and guidance questions which can help assess whether, within a national context, a transition is taking place from violation to implementation of the right to live in the community.

1. The right to live in the community: the basics

1.1. The core right

Living independently and being included in the community is closely linked with other human rights such as equality and non-discrimination, physical and mental integrity, liberty, freedom from inhuman or degrading treatment or punishment, autonomy, legal capacity, privacy, family rights, and freedom of movement. Yet living in the community is more than the sum of these rights.

The right to live in the community is linked with how health, education, social support systems and the labour market are shaped. It is contingent on the accessibility of public spaces and services. But again, living in the community is not only a reflection of accessibility.

Article 19 of the CRPD embodies a positive philosophy, which is about enabling people to live their lives to their fullest, within society. The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one's life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. 'Neutralising' is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.

The world over, people live in various settings that together make up the range of living schemes in a given society. In some places, people of all ages live with their extended families; in other communities, members of nuclear families cohabitate only until a particular stage of life, after which they move out of their parents' house to live alone, with housemates, or with their own newly-established families. In some societies, communal life is more common, while in others individual lifestyles are the norm. Whichever the scheme, living as a part our communities – from local to global – serves as the basis for everything we do in life.

Living and being included in society is about being able to share in those schemes available and utilised by people in that society. It is about the opportunity to access the public sphere: being able to access housing markets and transportation systems just like anyone else, as well as “small places, close

to home”:³ being able to walk down the high street, to seek out friends and develop relationships with others. It is the opportunity to take risks, be responsible for one’s life, and in doing so, to be accorded the same, even if incomplete, safety net and protection available to other members of the community. Reaffirming the right to live in the community means making this baseline a reality for people with disabilities, and in that process responding to the preferences and desires of each person.

1.2. How a grasp of the right shapes the response

For most people, being a part of a particular society’s fabric is taken for granted and we might not even think about it. This is not the case when people with disabilities are concerned.

Whether due to stigma, inaccessibility of places, technologies, services and social structures, or lack of support within the community, people with disabilities have been isolated and segregated from their communities. People in many countries are confined to institutions, and therefore segregated from the community. In institutions, they are at risk from exploitation, violence and abuse. Countless more people with disabilities are physically located in their communities, but barred from meaningful participation in the life of their communities because either services are not available or communities are organised in ways that exclude them from participation.

While exclusion and segregation continue in many countries, steps are being taken in some places to remedy this longstanding injustice. This necessarily entails a process. For living independently and being included in the community to become a reality, social policy reform is needed, which has budgetary implications, involves multiple stakeholders, and necessitates coordination across government ministries and local authorities.

Whether a country has yet to begin or has begun this transition, a clear-cut and unambiguous understanding of what the right to live in the community means is crucial to ensure that the process unfolds in line with progressive realisation of the right. An incorrect understanding of the right to live in the community risks replacing one type of exclusion with another. Though

3. Louise Arbour, then United Nations High Commissioner for Human Rights, at the opening of the Convention on the Rights of Persons with Disabilities for signature, based on Eleanor Roosevelt, “The Great Question”, remarks delivered at the United Nations in New York on the occasion of the tenth anniversary of the adoption of the Universal Declaration of Human Rights on March 27, 1958: “Where, after all, do universal rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerned citizen action to uphold them close to home, we shall look in vain for progress in the larger world.”

governments increasingly recognise the inevitability of deinstitutionalisation,⁴ there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response.

This is not merely a theoretical concern. Countries which have already closed down large-scale institutions are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively to people with disabilities. Concern over this has been raised, for example, in Denmark.⁵ Such a solution compromises the individual's ability to choose or to interact with and be included in the community.

Some governments that have embarked on a deinstitutionalisation process are presenting small institutions and group homes as community-based responses. For example, in Hungary the government has recently issued a tender with European Union Regional Development Funds and Hungarian state funds to develop residential centres catering to up to 50 residents, and group homes of up to 14 residents.⁶ The more congregate the care, the less possibility there is for the individual to choose services and supports that meet their particular needs. Settings with this number of residents clearly exceed the capacity to offer individualised, self-directed care. Such settings also increase the likelihood of stigmatisation and work against the receptiveness of the general public to the rights of people with disabilities.

Some policies set upper limits on the number of people who can live together so as to guard against the development of congregate settings. For example, in Ireland, a 2011 report commissioned by the Health Service Executive recommended that if there are to be congregate settings, these should be established on the basis of no more than four people living together, and that as far as possible, each person has chosen to live there with the other three.⁷

Reducing the number of residents alone, however, does not on its own determine whether a living setting will reflect the principle of living independently and being included in the community. Individuals with disabilities may live alone or in groups of two and three and yet be secluded within and by these arrangements. Even small group homes, where a particular package of personal support services is attached, can result in restricting choices. These arrangements rest on a mistaken notion that living in the community is solely

4. See for example "Vision for Deinstitutionalization of Children in Bulgaria," (in Bulgarian), action plan by the State Agency for Child Protection, at <http://sacp.government.bg/deinosti/deinstitucionalizacia/>.

5. See reference to this concern by the Danish Centre for Equal Opportunity, in Academic Network of European Disability Experts (ANED), "The Implementation of Policies Supporting Independent Living for Disabled People in Europe: A Synthesis Report" (November 2009, amended January 2010), p. 19.

6. Tender by the Hungarian Ministry of National Resources, 16 November 2011, "Deinstitutionalisation – Social care homes component A", reference TIOP.3.4.1.A-11/1.

7. Health Service Executive, Ireland, "Time to Move on from Congregated Settings: A Strategy for Community Inclusion, Report of the Working Group on Congregated Settings", June 2011.

about physical placement in the community, rather than a way of life that is intimately linked with autonomy and choice. The solution lies in ‘unbundling’ disability-related supports from certain housing units, and providing people with disabilities with individualised supports which they can take to any housing option they choose in the housing market – whether social housing, rental, ownership, or any other form of housing tenure provided to people without disabilities.

Another troubling trend occurs when well-meaning efforts to provide individualised support fail to infuse these schemes with choice, and where these efforts do not include a component to increase the accessibility of the services offered to the general public.

These developing trends underscore the need for robust monitoring arrangements to ensure compliance with CRPD Article 19, and in turn, for understanding what Article 19 is about.

1.3. Articulation of the right: the UN Convention

1.3.1. General overview

The most developed articulation for the right to live in the community of people with disabilities is found in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD):

Article 19 – Living independently and being included in the community

States Parties to the present 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.

Article 19 is a foundational platform for the purpose of the Convention as a whole, which is the enjoyment of “all human rights and fundamental freedoms

by all people with disabilities” (Article 1 of the CRPD). A precondition for anyone to enjoy all their rights and fundamental freedoms is that they are within and among the community.

With its reference to equality, choice, and full inclusion and participation in the community, Article 19 invokes the “general principles” of the Convention, which set out the Convention’s underlying philosophy:

Article 3 – General principles

The principles of the present Convention shall be:

- a. respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- b. non-discrimination;
- c. full and effective participation and inclusion in society;
- d. respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. equality of opportunity;
- f. accessibility;
- g. equality between men and women;
- h. respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

In particular, Article 19 picks up on notions of respect for individual autonomy (Article 3(a) of the CRPD) as well as “full and effective participation in society” (Article 3(c) of the CRPD). With its focus on choice in the chapeau as well as sub-paragraph (a), Article 19 is also closely linked with Article 12 on equal recognition before the law and legal capacity. Choice is upheld by recognising one’s legal capacity to make choices and have them respected. These components are explored in detail in the sections below.

1.3.2. Living independently

The phrase “living independently” in the title of CRPD Article 19 is not defined in the text. It echoes the Preamble to the CRPD, paragraph (n) of which sets out that the global community recognise “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices”. More particularly, the phrase picks up on the first principle listed in the Convention, that of “[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (Article 3(a) of the CRPD).

“Living independently” does not mean that people with disabilities have to be independent in the sense of living a highly individual and self-sufficient life, at a distance from other people. It is, rather, based on a social model of disability which recognises that people are not limited in their choices because of any inherent feature or condition of the person him or herself, but by the social and physical environment in which they live. In enabling environments, things are not done *to* a person, but rather people are supported, just like anyone else, to make independent and autonomous (and in some cases supported) decisions. One disability studies scholar has suggested that, “[i]n reality, of course, no one in a modern industrial society is completely independent: we live in a state of mutual interdependence. The dependence of people with disabilities therefore, is not a feature which marks them out as different in kind from the rest of the population”.⁸ It is simply that the supports that some people with disabilities use, like mobility aids for example, are more obvious than the services and supports that all people access in order to live ‘independent’ lives in the community.

The notion of independence has been an important aspect in claiming equality for people with disabilities. The “independent living” movement has come to mean a demand for personal autonomy and control over one’s life, as well as demanding that the State provide effective services to enable people to live independently in the community.⁹ Independent living occurs if, in whatever living scheme one chooses to live one’s life, which as noted above could be one within the extended family, separate from it, or some other arrangement, one retains autonomy and control over one’s life and decisions while accessing the individualised supports needed to do so.

1.3.3. Choice, individualised support, accessibility of general services

The three key elements of Article 19 are: choice (in paragraph (a)), individualised support (in paragraph (b)), and making services for the general public accessible to people with disabilities (in paragraph (c)). In a given society, in which the right to live in the community is fully implemented, all three components are implemented. *General services* are constantly made more accessible to all, and *individualised support* bridges the gap to enable inclusion of each person, while providing maximum *choice* for the individual in the types of services provided and the manner in which they are provided.

The measure for success in implementing this right would be the actual lived experience of people with disabilities. As put succinctly and compellingly by

8. Mark Oliver, “Disability and Dependency: A Creation of Industrialised Societies” in: L Barton (ed.), *Disability and Dependency*, 1989, London, Falmer Press, pp. 83-4.

9. For more information see, for example, the website of the European Network on Independent Living, at www.enil.eu.

leaders from a self-advocacy network: Is the person enjoying a healthier and more satisfying life on their terms? Who is in charge? Does the individual have more control and choice? Is their participation in the community genuine and meaningful? Are their relationships authentic?¹⁰ Detailed analysis of these elements and how they derive from CRPD Article 19 appear in Chapter 3 below.

1.3.4. Link with legal capacity

Another facet of choice relates to its connection with recognising legal capacity. “Choice” in Article 19(a) of the CRPD, as well as “individual autonomy” in Article 3(a) are closely linked to the right to legal capacity, because one needs to be recognised as a person before the law to be able to decide one’s “place of residence” and “where and with whom” to live (Article 19(a)). Each person has “the right to legal capacity on an equal basis with others” (Article 12(2) of the CRPD). In some cases one may need assistance in exercising one’s legal capacity, and it is the State’s duty to ensure that such assistance is provided (Article 12(3) of the CRPD).¹¹

Curtailling the overall ability of individuals to make choices or have them respected naturally compromises opportunities to make more specific choices about where to live and how one’s life will look in relation to the community. At the same time, exclusion from life within the community increases the risk of legal capacity being denied. Little opportunity exists in the strictly controlled lifestyle, and lack of choice, inherent to institutional life, for an individual to voice his or her will.

The recent landmark cases at the European Court of Human Rights have exposed the human rights violations behind the coupling between denial of legal capacity and institutionalisation.¹² While many systems enabled guardians to place people in institutions en masse, these judgments imply that States will have to re-examine their laws which equate a guardian’s consent with that of the individual, and instead accord decisive weight to the individual’s decision.

Challenging institutionalisation is thus interwoven with challenging the legitimacy of guardianship and developing alternative models for supported

10. “Keeping the Promise: Self Advocates Defining the Meaning of Community Living,” March 2011, referred to by the Association for Self Advocacy, Croatia. Document prepared by leaders from the U.S.-based Autistic Self Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies. See <http://www.acf.hhs.gov/programs/add/adddocs/KeepingthePromiseofCommunitySABEFinalApproved.pdf>

11. The Commissioner’s Issue Paper, *Who gets to decide?: right to legal capacity for persons with intellectual and psychosocial disabilities*, CommDH/Issue Paper (2012)2, deals with Article 12 of the CRPD in more depth.

12. *Stanev v. Bulgaria*, Application No. 36760/06, judgment 17 January 2012, and *Shtukaturov v. Russia* App No. 44009/05, judgment 27 March 2008; see also Chapter 3 of this Issue Paper.

decision-making by the individual. Similarly, progress in implementing the right to live independently in the community will strengthen individuals' exercise of legal capacity. Thus, the implementation of Articles 12 and 19 of the CRPD go hand in hand, and progress in one area positively affects the other area.

1.3.5. Beyond non-institutionalisation

Many people with disabilities are still housed in institutions. A definition of “institution,” by now well known, has been proposed by the European Coalition for Community Living:

An institution is any place in which people who have been labeled 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.¹³

While physical placement within the community is necessary to ensure living in the community, it is not sufficient. Article 19 of the CRPD posits a positive philosophy of “living in the community, with choices equal to others” and “full inclusion and participation in the community,” against the inverse, which is “isolation or segregation from the community.”

The right to live in the community is therefore more than the right not to live in a large institution. Community living may be compromised even where no institutions exist. People with disabilities may be isolated in various ways even when physically present in the community, if they are not provided with sufficient supports to ensure their participation and inclusion in the community or are subject to models of support that perpetuate loss of control, impose restrictions on choice, and provide limited or no meaningful access to the community.

Other living arrangements, such as living alone or in small groups within the community, may also perpetuate isolation and segregation, which are the hallmarks of institutional life. Isolation and segregation could occur due to the number of people residing in a particular setting which negates the exercise of individual choice in the everyday and creates a magnet for bringing services inside the setting rather than each person interacting in many and diverse ways with the community. Isolation and segregation could occur due to an imposed regimented way of life, the paternalistic manner in which services are provided, the lack of every-day choices, or disincentives to gaining independence such as by providing bundled services that make the receipt of one type of service conditional upon receiving other services. Various dimensions must

13. European Coalition for Community Living: <http://www.community-living.info/?page=205>.

be examined beyond the actual walls of the place of residence. These include not only the physical size and structure of the residence, but also respect for rights, choice and self-determination, qualities and attitudes of providers, actual access to community life, and how support and access needs are met.

The following examples from the lives of individuals who reside physically within the community illustrate this point: A person living in a state-run group home with seven other housemates has little chance of choosing her housemates or having privacy within her home. Because the house is run for a large group, and especially if she needs support for daily living or in accessing the community, she will likely be subject to restrictions that impede possibilities for a self-directed life, including rules about when she can leave and with whom and how often, and when to retire for the night. Particularly, the possibility for her to develop personal relationships and express her sexuality will be limited. Likewise, housing communities comprised of a number of buildings designated for people with disabilities within a neighbourhood are proposed in some contexts as an alternative to segregation. By definition, however, the ability to connect from within these settings with the larger community of people with and without disabilities – chance meetings with neighbours or actively seeking out connections – is inhibited.

Finally, even living alone in one's home in the community does not guarantee inclusion in the community if support services are not geared toward enabling inclusion. People with disabilities who need support to find and retain meaningful employment are often provided only with the option of a sheltered workshop or a day-centre, rather than a chance to venture into the world and find employment according to one's talents and preferences, with the opportunity for advancement, and ability to take risks and receive support accordingly.

Often when States provide statistics about individuals living in the community, this data is comprised of the numbers of individuals living in congregated settings, such as group homes, where choice and full inclusion in the community are inherently compromised. The analysis below of Article 19's core components, an overview of the ways in which violations of Article 19 occur, and the indicators and guidance questions in the Appendix to this Issue Paper, help expose critical nuances that differentiate between inclusion and continued segregation.

2. International law and policy

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) provides the most developed articulation of the right to live in the community of any international human rights instrument to date. However, the right to live in the community with choices on an equal basis with others has evolved from an array of international legal norms and political commitments emanating from the United Nations, Council of Europe and European Union, and is based on empirical research conducted in several jurisdictions. This chapter sets out some of the developments in international law, focusing on the interrelationship between the work of international bodies and Article 19 of the CRPD.

2.1. United Nations

The UN Committee on the Rights of the Child has commented on health, social and housing services available to children with disabilities, on their wide-scale institutionalisation, and on the need for data collection.¹⁴ It has also expressed concern about stigma against children with disabilities which results in them being hidden at home.¹⁵ The Committee has advocated for anti-discrimination laws to provide protection from discrimination in the areas of social security, healthcare, education and provision of goods and services,¹⁶ and has noted the multiple forms of discrimination experienced by children living in poverty, including children with disabilities.¹⁷ The CRPD's treaty body, the Committee on the Rights of Persons with Disabilities, has noted concerns about limited community support services.¹⁸

For the UN High Commissioner for Human Rights (OHCHR), key elements of implementing Article 19 of the CRPD are an “explicit legal recognition” of the right,¹⁹ and providing support services on the basis of the individual's own choices and aspirations.²⁰ The OHCHR's Europe regional office has

14. UN Committee on the Rights of the Child, Concluding observations: Bulgaria, 6 June 2008, CRC/C/BGR/CO/2.

15. UN Committee on the Rights of the Child, Concluding observations: Romania, 12 June 2009, CRC/C/ROM/CO/4.

16. UN Committee on the Rights of the Child, Concluding observations: the Slovak Republic, 10 July 2007, CRC/C/SVK/CO/2, para. 39.

17. UN Committee on the Rights of the Child, Concluding observations: Belgium, 11 June 2010, CRC/C/BEL/CO/3-4, paras. 31-32.

18. See UN Committee on the Rights of Persons with Disabilities, Concluding Observations: Tunisia, Fifth session 11-15 April 2011, CRPD/C/TUN/CO/1 and Concluding Observations: Spain, Sixth session, 19-23 September 2011, CRPD/C/ESP/CO/1

19. United Nations Office of the High Commissioner for Human Rights (OHCHR), “Thematic study of the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities”, 2009, A/HRC/10/48.

20. *Ibid.*, paragraph 51.

weighed in on community living, highlighting the need to monitor rights in community-based services.²¹

2.2. Council of Europe

European Court of Human Rights

Several provisions in the European Convention on Human Rights (ECHR) are relevant to establishing the right to live in the community. The Grand Chamber of the European Court of Human Rights has recently, and for the first time, found a violation of Article 5 of the ECHR (which sets out the parameters of the right to liberty) in relation to someone living in a social care institution. The applicant, Rusi Stanev, had been institutionalised for nine years. The distance and isolation from the community he experienced, the institution's regimented daily schedule, the rules on leave of absence, the lack of choice in everyday matters, and the lack of opportunity to develop meaningful relationships, as well as the fact that Mr Stanev had been deprived of legal capacity, were all factors that led the Court to find a violation of the right to liberty within the meaning of Article 5 of the ECHR.²²

Article 8 of the ECHR protects the right to respect for private and family life, home and correspondence. It most directly invokes rights that are infringed when a person is isolated or segregated from the community. Although cases brought by people with disabilities alleging that the State has failed to guarantee access to the physical environment have to date been unsuccessful,²³ in other cases the Court has clarified that the concept of private life embraces a person's "physical and psychological integrity" as well as the "development, without outside interference, of the personality of each individual in his relations with other human beings".²⁴ In a number of pending cases people with disabilities have asserted that their Article 8 rights have been violated by the failure of a State to provide laws and policies to enable them to take decisions on an equal basis with others.²⁵ The lacuna of cases brought to the Court by people with disabilities is unsurprising, given the severe barriers in accessing justice they face.

21. Camilla Parker, "Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions", Office of the High Commissioner for Human Rights European Regional Office, Brussels, 2011.

22. *Stanev v. Bulgaria*, Application No. 36760/06, judgment 17 January 2012.

23. See for example *Botta v. Italy* (op cit), *Sentges v. the Netherlands*, Application No. 27677/02, judgment 8 July 2003, *Zehlanova and Zehnal v. Czech Republic*, Application No. 38621/97, judgment 14 May 2002, and *Farcas v. Romania*, Application No. 32596/04, admissibility decision 14 September 2010.

24. *Botta v. Italy*, Application No. 21439/93 (1998) 26 EHRR 241.

25. For a recent example of the powerful role of Art 8 in relation to other disability-related issues, see *Shtukaturov v. Russia* App No. 44009/05, judgment 27 March 2008, [86]–[96] in which the Russian guardianship system was held to violate Art 8 of the ECHR because the total and indefinite loss of decision-making power it entailed was disproportionate to the aims it sought to achieve.

European Social Charter

The European Social Charter contains a provision that applies specifically to people with disabilities, the goal of this provision being the “effective exercise of the right to independence, social integration and participation in the life of the community”.²⁶ States, according to the Charter, should promote “full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure”.²⁷ The implications are threefold: States must (a) assess barriers and identify necessary support measures; (b) provide technical aids and appropriate housing support arrangements; and (c) provide other types of support services such as personal assistance and auxiliary aids.²⁸

States must adopt laws and policies to implement the European Social Charter effectively, including comprehensive non-discrimination legislation covering “both the public and private sphere in fields such as housing, transport, telecommunications and cultural and leisure activities and effective remedies for those who have been unlawfully treated”.²⁹ In addition to such legislation, “a coherent policy on disabilities” needs to be adopted, accompanied by “measures to achieve the goals of social integration and full participation of persons with disabilities”. These measures should be codified and their implementation coordinated.³⁰ In addition to this interpretation of the Charter, two Charter cases are of relevance to children with disabilities, in connection with Article 17 of the Charter (the right of children and young persons to social, legal and economic protection).³¹ In the first of these, *Autism Europe v. France*, the Committee advanced its jurisprudence on providing services to people with disabilities, establishing that “[w]hen the achievement of one of the rights in question is exceptionally complex and particularly expensive to resolve, a State Party must take measures that allows it to achieve the objectives of the Charter within a reasonable time, with measurable progress and to an extent consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact that their choices will have for groups with heightened vulnerabilities as well as for others persons affected including,

26. Article 15 of the European Social Charter (Revised), Strasbourg, 3 May 1996.

27. Article 15(3) of the European Social Charter (Revised), Strasbourg, 3 May 1996.

28. General Introduction to the 2008 Conclusions of the European Committee of Social Rights under the Revised European Social Charter, 9. Statement on technical aids and support services (Article 15(3)).

29. *Ibid.*

30. European Committee of Social Rights (November 2008), p. 15.

31. See the collective complaint *MDAC v. Bulgaria* engages directly with segregation of children with intellectual disabilities and the denial of their education (Collective complaint No. 41/2007, decision 10 June 2008). The collective complaint of *Autism Europe v. France* concerned the insufficient education provided to children with autism (Collective complaint No. 13/2002, decision 7 November 2003).

especially, their families on whom falls the heaviest burden in the event of institutional shortcomings”³²

Committee for the Prevention of Torture

The Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) examines the rights of people deprived of their liberty so as to prevent torture and other ill-treatment.³³ The CPT visits social care institutions for children, and adults, as well as psychiatric wards and hospitals. For the CPT, inadequate community-based services forcing people with disabilities to remain in psychiatric establishments is a “highly questionable state of affairs”,³⁴ because such establishments “pose a significant risk of institutionalisation for both patients and staff”, which can have “a detrimental effect on patient treatment”.³⁵ The development of community-based alternatives are “a very favourable development” as long as the services “provide a satisfactory quality of care”.³⁶ During its visits to places of detention the CPT has made several recommendations, including one on developing “a national plan for mental health which addresses the challenges faced by psychiatric institutions and social care homes (including funding issues) and seeks to develop a process for deinstitutionalisation [...]”,³⁷ and another on providing services which prepare people previously confined to such institutions to be re-integrated into the community.³⁸

Committee of Ministers

In April 2006 (eight months before the UN General Assembly adopted the CRPD), the Committee of Ministers adopted the “Council of Europe Disability Action Plan 2006-2015”,³⁹ which foreshadows many CRPD provisions. Focusing on “enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live”, the Action Plan requires strategic policies which support the move from institutional care to community-based settings ranging from independent living arrangements to small group homes. Such policies should be flexible, covering

32. *Autism Europe v. France* (op cit), para. 53.

33. European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Strasbourg, 26 November 1987, Article 1.

34. CPT Standards, CPT/Inf/E (2002) 1 - Rev. 2010, para. 57.

35. *Ibid*, para 58.

36. *Ibid*.

37. Report from visit to Bosnia and Herzegovina in 2007, published 14 October 2009, CPT/Inf (2009) 25, para 110.

38. Report on visit to Montenegro in 2008, CPT/Inf (2010) 3, 9 March 2010, para 84

39. Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015 (adopted by the Committee of Ministers on 5 April 2006).

programmes which enable persons with disabilities to live with their families and recognising the specific needs of individuals with disabilities requiring a high level of support.⁴⁰ Specific actions include recognising and valuing the role of carers and offering them appropriate training and support, and facilitating the ability of people with disabilities to employ personal assistants and make their own decisions including by accessing advocacy services.⁴¹

Since then, the Committee of Ministers has adopted a number of relevant Recommendations,⁴² including one on deinstitutionalisation and community living of children with disabilities.⁴³

Parliamentary Assembly

The Parliamentary Assembly of the Council of Europe adopted a Resolution on access to rights for people with disabilities and their full and active participation in society,⁴⁴ finding it “imperative” that the right to live in the community be upheld. The Resolution sets out three actions for governments. First, states should, “commit themselves to the process of deinstitutionalisation by reorganising services and reallocating resources from specialised institutions to community-based services”. Second, they should “provide adequate and sustained assistance to families, above all through human and material (particularly financial) means, to enable them to support their disabled family member at home”. And third, they should “develop effective, independent inspectorates to monitor existing institutions”.⁴⁵

Commissioner for Human Rights

Finally, the work of Thomas Hammarberg, the Commissioner for Human Rights, has focused on people who find themselves in positions of vulnerability, including children and adults with disabilities. The 2008 issue paper on human rights and disability calls for the development of inclusive community-based services.⁴⁶ The Commissioner has highlighted the need for states to provide services to parents to enable them to keep their children with disabilities at

40. See Action Line 8 of the Disability Action Plan.

41. Other action lines of relevance are numbers 3 on information and communication, 4 on education, 5 on employment, 6 on the built environment, 7 on transport, 10 on rehabilitation and 11 on social protection.

42. See, for example, Committee of Ministers of the Council of Europe (2009) Recommendation on monitoring the protection of human rights and dignity of persons with mental disorder, CM/Rec(2009)3, adopted on 20 May 2009; Recommendation on ageing and disability in the 21st century, CM/Rec(2009)6, adopted on 8 July 2009; Recommendation on Achieving full Participation through Universal Design, CM/Rec(2009)8, adopted on 21 October 2009; and Recommendation on the education and social inclusion of children and young people with autism spectrum disorders, CM/Rec(2009)9, adopted 21 October 2009.

43. Recommendation CM/Rec(2010)2, adopted on 3 February 2010.

44. Resolution 1642 (2009), adopted on 26 January 2009.

45. *Ibid.*, para. 8.

46. Thomas Hammarberg, “Human Rights and Disability: Equal Rights for All”, CommDH/Issue Paper (2008) 2.

home, thus avoiding institutionalisation.⁴⁷ Commissioner Hammarberg has shed light on the situation of people with intellectual disabilities being housed in social care institutions,⁴⁸ and the practice of depriving people with disabilities of their legal capacity, stripping them of many rights including the right to decide where to live,⁴⁹ a topic dealt with in an Issue Paper published alongside the instant one.⁵⁰ People with disabilities face particular difficulties in accessing the right to housing, Commissioner Hammarberg has noted.⁵¹ States must “ensure access to transport, housing, cultural and leisure activities,” as well as home adaptations and home help. Commissioner Hammarberg warns that “any measure that leads to the discontinuation of a person’s rehabilitation or poses a risk to his or her health or capacity is not permitted”.⁵² The need for regular and independent monitoring of existing institutions is another point which has been made by Commissioner Hammarberg,⁵³ as well as by other bodies.

2.3. European Union

The European Union has made notable developments on the right to live in the community of people with disabilities. At the level of EU law, the Charter of Fundamental Rights of the European Union contains some relevant provisions.⁵⁴ The EU’s accession to the CRPD brings the UN treaty directly into EU law,⁵⁵ and the EU is obliged to combat discrimination within its competencies.⁵⁶

At the policy level, the European Commission’s “European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe” focuses on the elimination of barriers and identifies areas where EU-level action can

47. Thomas Hammarberg, “Society has an obligation to support abandoned children and offer them a positive home environment - also when budget resources are limited”, Viewpoint, 28 December 2009.

48. Thomas Hammarberg, “A neglected human rights crisis: persons with intellectual disabilities are still stigmatised and excluded”, Viewpoint, 14 September 2009.

49. Thomas Hammarberg, “Persons with mental disabilities should be assisted but not deprived of their individual human rights”, Viewpoint, 21 September 2009.

50. Thomas Hammarberg, “Who gets to decide?: right to legal capacity for persons with intellectual and psychosocial disabilities”, CommDH/Issue Paper(2012)2.

51. Thomas Hammarberg, “Recommendation of the Commissioner for Human Rights on the implementation of the right to housing”, 30 June 2009, CommDH(2009)5.

52. Ibid, para. 4.3.1.

53. Thomas Hammarberg, “Inhuman Treatment of Persons with Disabilities in Institutions”, Human Rights Comment, 21 October 2010.

54. See Articles 21 and 26 in particular.

55. Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC), OJ L 23, 27.1.2010, p. 35.

56. Treaty on the Functioning of the European Union, Article 10. This states thatn when “defining and implementing its policies and activities” the EU must “aim to combat” discrimination on various grounds, one of which is disability.

complement initiatives by member states.⁵⁷ Developing community-based services are member state competencies, but EU law has a role to play to ensure that goods and services for people with disabilities are provided in a non-discriminatory way, even though the only binding non-discrimination directive so far is limited to employment and occupation.⁵⁸ The European Commission provides various funding mechanisms to member states, including the Structural Funds, and although these need to be provided without discrimination,⁵⁹ concern has been raised about how these funding streams are deployed to bolster institutions, rather than develop community-based supports.⁶⁰ Lastly, EU-funded research has noted wide differences in the understanding of the right and numerous problems in its implementation.⁶¹

As has been set out in this chapter, the content of Article 19 of the CRPD is a synthesis of a wealth of laws, standards, and statements emanating from European and other bodies. It is an articulation of equality and inclusion, and a declaration of independence and interdependence. The next chapter sets out what the right to live in the community looks like in practice.

57. European Commission, “European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe”, COM(2010)0636 final.

58. Council Directive 2000/78/EC (Employment Equality Directive).

59. Article 16 of the General Regulation on the Structural Funds provides that steps need to be taken to prevent any discrimination on the basis of disability and to ensure accessibility in the implementation of the funds, Council Regulation No. 1083/2006, p. 25.

60. See European Commission, “Second Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities”, June 2009, p. 218; Jan Pfeiffer et al, “Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care”, 2009, Brussels, European Commission; and Camilla Parker et al, European Coalition for Community Living, “Wasted Time, Wasted Money, Wasted Lives - A Wasted Opportunity?”, March 2010.

61. Townsley, R. with Ward, L., Abbott, D. and Williams, V., “The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report”, 2009, Academic Network of European Disability Experts (ANED). See also European Foundation Centre (2010). European Foundation Centre (2010) *Study on Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities*, (VC/2008/1214): Final Report for the DG Employment, Social Affairs and Equal Opportunities of the European Commission, Brussels.

3. Implementing the right to live in the community

Segregation and institutionalisation of people with disabilities have a long and tragic history. The notion that people with disabilities can – and should – live independently and be included in the community is, however, gaining momentum. Though Article 19 of the CRPD clearly has implications for deinstitutionalisation and developing services, adhering to its spirit requires a sea change, requiring us to move beyond the subtly-patronising and sterile language of needs and services and towards enabling people to get on with their lives as they want to craft them.

As the previous chapter demonstrated, international law provides a foundation for the right to live in the community to be implemented in practice. There are numerous examples of good practice which fall outside the remit of this paper. The goal of the present chapter is rather to provide guidance against which the process of and progress in implementing the right to live in the community can be examined: Are efforts aligned with a human rights-based approach? Are they true to the spirit of Article 19 of the CRPD?

Some States have undergone a process to come closer to that goal, by shifting from institutional services to community-based services, or developing completely new services and supports where none existed. These advances are to be commended, and should be broadened, systemised, anchored in law and policy, and aligned with human rights standards.

3.1. What constitutes implementation – Drawing guidance from CRPD Article 19

The overarching objective of Article 19 is full inclusion and participation in society. Its three key elements are choice (19(a)), individualised support (19(b)), and making services for the general public accessible to people with disabilities (19(c)).

3.1.1. Choice

Choice plays a crucial role in implementing Article 19. Life in institutions severely inhibits the possibility of activating one's choice, even in the most basic way. Institutions are therefore not an option where “choices equal to others” can be practiced. Choice includes giving a person the opportunity to weigh in on how alternatives are shaped. The more societal structures and services are designed to include people with disabilities, the less the need to rely on individualised support. Put another way, individualised support does not diminish the need for constantly broadening community facilities and services in order

to make them more inclusive. Still, individualised support will be needed to enable inclusion of all people with disabilities in the community. In shaping these supports, the choice of the person with a disability should be a guiding principle. The need for support does not justify inhibiting or regulating people with disabilities in a way in which people without disabilities are not regulated.

Choice has direct bearing on the way support is provided, and is linked with the existence of alternatives. As is often the case, if only one alternative to institutionalisation is provided, the person cannot make any real choice. “You have choice, but at the moment we have only one alternative to offer” is a common pronouncement to people with disabilities, when drug therapy, congregate group settings in which people are clustered together only on account of their disability, or segregated workplaces are offered as an alternative to institutional life or segregated life within the community.

3.1.2. Individualised support services

Article 19(b) of the CRPD sets out the right for people with disabilities to have “access” to various services. To have access to a range of services presupposes that such services exist, and are within the reach of each person with disabilities. The types of services which are mentioned are “in-home, residential and other community support services, including personal assistance”, and these services are to be provided if they are “necessary” in order to do two things: first, “to support living and being included in the community”, and second, “to prevent isolation or segregation from the community”.

These qualifiers hint at the need to set a standard of support below which inclusion is not possible; a standard, therefore, from which States cannot derogate. For example, if people with high support needs are not provided the individualised supports they require to access various places of their own choosing or interact meaningfully with members of the community and, as a result, they remain home most of the day or move together as one large group from their home to a workplace to a recreation centre, this paragraph’s requirement cannot be considered as fulfilled.

Various dimensions of support are required to enable inclusion in the community. Support must allow for the choice generally experienced by people without disabilities in typical life activities, and not be strictly limited to what the particular provider has to offer. Support, which may be necessary in various areas of life, such as around finding and maintaining employment, determining one’s diet, spending money, travel, and relationships, should be value-neutral. The individual supported should be able to adopt or reject that support, and choose to make a different decision altogether. Support should accommodate relationships instead of discouraging them (for example, often people may lose their support services if they marry or have children). Agencies providing

support should demonstrate that they measure their success by how well they are responding to the preferences and desires of the individuals they support in relation to their life as community members.

Choice and control over the support needed to live and be included in the community are of paramount importance in the area of support services, in particular personal assistance. This is particularly so since these services, which are indispensable for individuals who need a high level of support, touch on the most intimate parts of life, such as daily care. The identity of the support person and the relationship between the support person and the individual being supported are crucial. Opportunities should be provided for people with disabilities who so desire to have utmost control over these matters, including hiring, employing, supervising, evaluating, and dismissing, their personal assistant. This may require access to independent planning and facilitation services, in order to help develop life plans for life in the community and pursue these plans, as well as access to advocacy services in order to navigate the system and protect one's rights and interests.

Resources

States sometimes justify the dearth of community services by resorting to the lack of available State resources. The right to live in the community could well be characterised as a hybrid right which contains aspects of economic, social and cultural rights. These types of rights, according to Article 4(2) of the CRPD, are to be implemented progressively, “to the maximum of [the State’s] available resources.” However, even where progressive realisation is the case, States are under an obligation to show that they are taking steps to the maximum of their available resources to implement this right. Each year’s performance must be measurably better than the previous year’s performance and the State can be held accountable for such progress. The Appendix to this Issue Paper proposes milestones for measuring this progress.

It should be noted that other aspects, which have to do with civil and political rights, take effect immediately, as explicitly made clear by the continuation of Article 4(2) – “without prejudice to those obligations [...] that are immediately applicable according to international law.” One such right is non-discrimination; it would not be lawful for a State to provide services for, e.g., people with disabilities of a certain age, or men with disabilities, or people with only certain types of disabilities and not others (such as complex disabilities).⁶² Another example of a civil and political right is the right to liberty (set out in Article 14 of the CRPD, and Article 5 of the European Convention on Human

62. The approach taken by the United States Supreme Court in the famous *Olmstead* case and in the many subsequent cases identifies the underpinnings of the right to live in the community in the anti-discrimination mandate of the Americans with Disabilities Act, see *Olmstead v. L.C.*, 527 U.S. 581 (1999).

Rights). The detention of people with disabilities in institutions is a practice which must be terminated as it is a violation of this right.

Costs often serve as an excuse for maintaining the status quo. Resources are needed to fund the strengthening, creation, and maintenance of community-based services. For a time, there may be a need for additional resources, particularly during the process of phasing out residential institutions and replacing them with community-based services and supports. When this process is completed, however, studies have shown that there can be cost savings once services and supports are transferred to the community and institutions are phased out.⁶³ In contexts where institutions are not prevalent but people with disabilities are marginalised within their communities, they and their families will need supports in their everyday life to enable community inclusion and participation. In both scenarios, the cost component would be mitigated as services for the general public are made accessible to people with disabilities – another key component of Article 19 implementation to which this Issue Paper now turns.

3.1.3. Inclusive community services

As set out above, Article 19 obliges States to ensure that there are specific services for people with disabilities to enable them to live and participate in the community and be prevented from being segregated or isolated. Article 19(c) of the CRPD sets out that States should also ensure that, “[c]ommunity services and facilities for the general population are available on an equal basis to people with disabilities and are responsive to their needs”.

A key component to achieving inclusion in the community is ensuring the inclusiveness of existing public services (education, health, vocational training and support in finding and maintaining employment, transportation, etc.). The more inclusive these services are, the less the need to develop specialised services catering to the individual, and the better society as a whole is served. Critically examining the range of existing services enables those services to become more inclusive of, and responsive to, people with disabilities and the population in general.

For example, ensuring that providers of general health services are trained to serve people with different types of disabilities (e.g., training all practitioners serving the general public about how to communicate with a person with an

63. James W. Conroy, “The Costs of Supporting People with Developmental Disabilities in Institutional Versus Community Settings” (revised June 2004), Center for Outcome Analysis, US. See also: Jones, P., Conroy, J., Feinstein, C., & Lemanowicz, J. (1984). “A Matched Comparison Study Of Cost Effectiveness: Institutionalized And Deinstitutionalized People”, *Journal of the Association for Persons with Severe Handicaps*, 9, 304-313; and Stancliffe, R.J. & Lakin, C. (2004) “Costs and outcomes of community services for persons with intellectual and developmental disabilities”, *Policy Research Brief 14(1)*, Minneapolis, University of Minnesota, Research and Training Center on Community Living.

intellectual disability) reduces the need for creating specialised services for people with disabilities. This is more cost-effective and avoids the risk of segregation and sub-standardisation of a specialised service. In the area of employment, rather than developing specialised workshops for people with disabilities, individual inclusion in regular workplaces can be facilitated by on-site and informal support from work colleagues. Fostering these types of supports also benefits the employment integration of other marginalised groups.

The provision in Article 19 that community services and facilities for the general public be available and responsive to the needs of people with disabilities is of particular importance in contexts where designated entitlements for people with disabilities are scarce. In some States, services for the general population are limited, making it difficult to engage in an effective discourse around services for people with disabilities. The right to live in the community is as relevant in these settings as in those with a developed discourse, but indicators for monitoring implementation and progress must take account of the different contexts.

Where institutions are a State's predominant response to the needs of people who require more intensive support, monitoring the implementation of the right to live in the community is particularly needed. Such monitoring should examine, uncover, and expose policies and funding schemes which favour institutions over community settings. As regards community-based schemes, monitoring should look deeply at their nature and quality.

Sometimes neither institutions nor targeted community-based services exist, perhaps because of a general lack of services to populations at risk of poverty and marginalisation. In these cases, people with disabilities may live largely with their families. Monitoring should then focus on examining the inclusiveness of the existing systems serving the community at large, such as health, transportation, education and employment, rather than focus on residential facilities and enveloping services. Suggestions for conducting this monitoring, which focus on incorporating the disability perspective into services for the broader population (thus off-setting some of the resource arguments), are provided in the Appendix to this Issue Paper.

Accessibility and reasonable accommodation

Adjustments to how regular services are run have links with other CRPD provisions. Article 9 of the CRPD sets out a general State obligation on accessibility:

“[t]o enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and

*communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas”.*⁶⁴

Services thus may need to be adjusted at the macro level to include people with disabilities.

Another CRPD provision, Article 5, seeks to make micro adjustments to services to enable an individual to access services and enjoy human rights. This provision sets out the prohibition of disability-based discrimination. Disability-based discrimination means “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field”. Discrimination need not be voluntary to be considered discrimination, as long as negative differential treatment is the result.

Importantly, the CRPD sets out that the failure to provide “reasonable accommodation” is a form of disability-based discrimination. The term “reasonable accommodation” is defined as the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (CRPD Article 2).

The negative duty not to discriminate – which includes the positive duty to provide reasonable accommodation – falls on the State. The CRPD also sets out an obligation on the State to “take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise” (Article 4(1)(e) of the CRPD). Thus, the State must ensure that reasonable accommodation is being provided, for example, by a private transport company, a provider of public health services, or even an individual personal assistant. The central authorities have a duty under international law to ensure that even services run by local or municipal governments do not discriminate, because the State has a duty “to ensure that public authorities and institutions act in conformity with the [CRPD]” (Article 4(1)(d) of the CRPD).

3.2. Violations of the right to live in the community

Articulating the various ways in which the right to live in the community is violated is a necessary step towards monitoring whether and how this right is restored in law, policy, and practice. The following analysis is the reverse side of how implementation is understood.

64. Article 9(1) of the CRPD.

Isolation of people with disabilities exists in various contexts. Institutionalisation of people with disabilities is one of the most egregious forms of isolation, and still prevalent in many Council of Europe member states. Yet other forms of isolation must also be exposed and monitored. As discussed above, the failure to make general public services accessible to people with disabilities and the failure to provide individualised community-based supports are also primary causes of isolation. In addition, where institutions have been closed, the new services may be physically located in the community but retain isolating features. These various forms of isolation are reviewed in greater depth in the sections below.

The indicators and guiding questions in the Appendix to this Issue paper capture the diverse forms that isolation takes, such as actual confinement of people with disabilities in institutions, assignment to congregate care as the only option for receiving support, or lack of support of any kind in the community.

3.2.1. Segregation in institutions

Today, millions of people with disabilities around the world continue to live segregated in institutions. In 2007, an international study estimated that there are nearly 1.2 million people living in residential institutions for people with disabilities in European Union member states (the study included Turkey, but excluded Germany and Greece for which no data was available).⁶⁵ For the great majority of these people, there is no data on the size of institutions in which they live. No data is available on how many people live in residential institutions for people with disabilities in the wider Council of Europe region.

High levels of institutionalisation go hand-in-hand with lack of community-based options: lack of community-based alternatives denies choice, as people with disabilities in need of support in their everyday lives have no viable choice other than living in an institution. The corollary is that life in an institution degrades a person's ability to make decisions. Deinstitutionalisation must therefore be accompanied by measures to augment a person's decision-making capacity. This highlights again the need for policy makers to deal with legal capacity law reform at the same time as implementing the right to live in the community.

Segregated places of treatment, which serve as residence as well, have the characteristics of institutions and should also be scrutinised, including homes for older people, nursing homes, social care homes, psychiatric hospitals or departments, rehabilitation centres, and in some countries outside Europe

65. Jim Mansell, Martin Knapp, Julie Beadle-Brown and Jeni Beecham (2007) "Deinstitutionalisation and community living – outcomes and costs: report of a European Study", p. 26.

– healing camps. Other types of institutions to be looked at are orphanages and general social welfare homes. Though not necessarily defined as institutions for people with disabilities, these institutions often house many children and adults with disabilities. All of these types of segregated residential institutions for persons with disabilities stand in violation of Article 19 of the CRPD.

Definition of an institution

When determining what constitutes institutionalisation, the concept of “total institution” as defined by the well-known sociologist Erving Goffman could offer guidance. According to Goffman, who studied institutions in depth, the total institution is characterised by a system in which people are grouped together and their lives are regulated by the rules of that one system. This is contrary to a basic social arrangement in modern society in which “the individual tends to sleep, play and work in different places with different co-participants, under different authorities, and without an over-all rational plan”.⁶⁶ Goffman posited that the central feature of total institutions can be described as “a breakdown of the barriers ordinarily separating these three spheres of life”. He explained how in institutions, “all aspects of life are conducted in the same place and under the same central authority”. Second, “each phase of the member’s daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together”. And third, “all phases of the day’s activities are tightly scheduled, with one activity leading at prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials.” The system brings these three activities together “into a single rational plan purportedly designed to fulfil the official aims of the institution”. Psychiatric hospitals and social care institutions are examples of what Goffman calls “total institutions”.

The possibility for self-determination within institutions is severely inhibited, as lives are managed in a group setting and subject in every aspect to the system’s rules. Goffman observed that choice is denied in every aspect of life, from decisions about where and with whom to live, to life’s smallest details: when and what to eat, when to sleep and wake up, what to do, when to leave and enter the premises. Consequently, institutionalisation severely limits autonomy, which in turn contributes to the chronicity of one’s condition. With one’s actions and opportunities completely controlled by the institutional system, disabilities increase, making chances for successful reintegration into the community all the more unlikely.⁶⁷

66. Ervin Goffman, “On the Characteristics of Total Institutions”, 1959, Penguin.

67. Erving Goffman, “Asylums: Essays on the Social Situations of Mental Patients and Other Inmates” (1961).

Institutionalisation increases the risk of exploitation, violence and abuse

Time after time, deeply disturbing stories of torture, abuse, or acute neglect in institutions surface and enter public consciousness. Reports on some of the most egregious human rights violations emerge from every country which has institutions, and abuses and neglect occur the world over. A few examples from the last decade include several men in Romanian institutions dying of malnutrition and hypothermia,⁶⁸ people in psychiatric hospital in Denmark being strapped to a hospital bed for several days,⁶⁹ people with learning disabilities in a small institution in the UK being beaten by staff,⁷⁰ inadequate fire safety procedures in an institution leading to deaths of children with disabilities in Estonia,⁷¹ severe overcrowding and poor material and hygienic conditions in a psychiatric facility in Ghana,⁷² and using straps and electricity to enforce discipline in children with disabilities in the United States.⁷³

The propensity towards violence is inherent to institutions, because life there is conducted as a closed system typically far from the public eye. Abuse and neglect is aggravated by non- or under-reporting due to the disempowered state of individuals living within the system, their own fear of retribution borne out of their dependency on the system for basic support, the lack of access to justice, including to mechanisms such as ombudsperson offices and courts, and disability-related communicational barriers. While monitoring closed settings is critical to minimising abuse within those settings, no amount of monitoring or closed-circuit TV cameras can rid institutions of their susceptibility to situations of abuse. The solution lies in dismantling these facilities, and developing more humane community-based services.

There is now ample evidence of increased risks of exploitation, violence and abuse as a result of living in an institution. Institutions are places where “unspeakable indignities” are more likely to happen than in community settings. As the former UN Special Rapporteur on Torture pointed out in 2008:

Persons with disabilities are often segregated from society in institutions, including prisons, social care centres, orphanages and mental health institutions. They are deprived of their liberty for long periods of time including what may amount to

68. Amnesty International, “Bulgaria and Romania: Amnesty International’s Human Rights Concerns in the EU Accession Countries, October 2005”, AI Index: EUR 02/001/2005 p. 9.

69. Report of the Government of Denmark on the visit to Denmark carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 11 to 20 February 2008, CPT/Inf (2008) 26, Strasbourg 25 September 2008, paras. 124-127.

70. David Brindle: “Abuse at leading care home leads to police inspections of private hospitals”, The Guardian, 1 June 2011. <http://www.guardian.co.uk/society/2011/may/31/abuse-at-leading-care-home>.

71. AFP: Estonia reels as 10 die in disabled orphanage fire, 20 February 2011 <http://www.france24.com/en/20110220-estonia-reels-10-die-disabled-orphanage-fire>.

72. UN Committee Against Torture, Concluding Observations of with regard to Ghana, 15 June 2011, CAT/C/GHA/CO/1, available at: <http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.GHA.CO.1.pdf>.

73. Mental Disability Rights International, “Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center”, 2010.

*a lifelong experience, either against their will or without their free and informed consent. Inside these institutions, persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. The lack of reasonable accommodation in detention facilities may increase the risk of exposure to neglect, violence, abuse, torture and ill-treatment.*⁷⁴

Institutionalisation critically interrupts life plans

Extracting people from ordinary settings of family and community and placing them in the segregated setting of an institution critically interrupts their life plans, or denies them an opportunity to develop a life plan in the first place. Having a life plan is essential to making choices. Without a sense of one's own life direction, there is no scope for making meaningful choices. Institutionalisation, isolation and social exclusion deny people with disabilities the opportunity to set a direction for their lives. This also sends the wrong message to the rest of society that people with disabilities are not deserving of making choices in pursuit of their life plans, with the necessary support.

Institutionalisation cuts off a person from family, friends, academic pursuits, and employment, among other aspects of life in the community. This disruption in relationships and endeavours leads to a breakdown in a person's life and individuality, creating formidable barriers to community reintegration. Once institutionalised, given the regimented lifestyle and absence of choice, it is difficult for a person to regain the ability to use personal skills for managing a life outside the institution, including voicing their will and intentions.

Contributing factors to institutionalisation

People with disabilities are sometimes forcibly confined to institutions by court order, or by laws which allow for the detention and forcible treatment of people who are assessed as having a mental illness of a nature or degree to "warrant" confinement according to those laws. Article 14 of the CRPD counters that and prohibits deprivation of liberty on the basis of a disability.⁷⁵

Many other people are institutionalised by force even if not by a formal court order or other procedure. If there is no infrastructure for services in the

74. Manfred Nowak, Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/63/175, 28 July 2008, para. 38.

75. See also the concluding observations of the UN Committee on the Rights of Persons with Disabilities, when examining Spain's compliance with Article 14 of the CRPD during its sixth session in September 2011. In this document, the Committee recommends to the Spanish government to, "review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorize involuntary internment linked to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned." UN Committee on the Rights of Persons with Disabilities, Concluding Observations: Spain, Sixth session, 19-23 September 2011, CRPD/C/ESP/CO/1, paragraph 36.

community, and a person needs support in everyday life, that person may have no real choice but to live in an institution. Moreover, real choice is curtailed if people with disabilities, their family members, surrounding support networks, and professionals are not made aware of a community-based option (and if no services exist to make that a real option).

The process may be such that a governmental authority (for example the welfare authority) is authorised to restrict a person from receiving support within the community. The system may incentivise placements in institutions and dis-incentivise referrals to the community. This may occur on the provider level – such as benefiting providers of institutional services with tax cuts while not doing so for providers of community-based services, or on the individual level – offering more support in an institutional setting over a community-based one. Financing schemes may prefer one setting over the other, for example if the per capita rate that the state offers to providers in an institution is higher than the pro capita rate offered to providers of community-based services, or the cap on individualised funding which the state makes available to individuals to purchase their own supports (as in direct funding schemes in some European countries).

It has also been observed that financing schemes by donors such as international development agencies, the World Bank, and the European Union may result in greater fiscal effort and investment in institutionalisation compared to investment in community-based supports, through the priorities and guidance attached to the funds or the absence of monitoring how the funds are directed. These donors and funding agencies could play a crucial role by increasing funding streams for the creation of community-based option and ending the funding of institutionalised settings.

3.2.2. Isolation within the community

Segregation from society occurs even where institutions do not exist or where they have been dismantled. An in-depth grasp of Article 19 from the preceding sections can help reveal nuanced forms of isolation that take place within the community.

At home

In those countries with no or very few institutions, but where prejudice and lack of support prevail, individuals with disabilities may live segregated within their communities in a manner relegating them to the farthest margins of society. People with disabilities may be confined to their own homes with no meaningful ties to the surrounding community. They may lack an opportunity to attend school or be employed. In extreme situations, they may be kept out

of sight – at times forcefully detained – by family members acting out of prejudice or helplessness in the absence of support.

In group homes

Other forms of segregation practiced in placing people with disabilities in congregate care which, though situated geographically in the community (for example in a residential neighbourhood), actually mirror institutional life. “Group homes”, often code for residential settings of between two and 15 people with disabilities, are an example of such settings.

In some countries where deinstitutionalisation processes are taking place or have concluded, group homes are sometimes introduced as *the* alternative.⁷⁶ It is thus particularly timely to identify this as an issue and prevent group homes from becoming the default solution that presumes to embody the principles of the right to live in the community.

The fact of grouping people together already sets the people apart from society as a group of their own, drawing the community’s gaze to disability (rather than to each individual person) and running counter to the obligation to promote “positive perceptions and greater social awareness towards persons with disabilities”.⁷⁷

The larger the group, the higher the risk of resembling an institution, as a person’s life is still dependent on and subject to the will and decisions of a narrow set of staff. Such settings, despite being physically placed in a city neighbourhood or a suburb, may operate as a closed-circuit system and be as isolated as an old-style mental institution. Particularly for those who require more intensive support, the chance for connecting with the community and making individual choices decreases. Because of size, strong forces are at play to bring services onsite, such as medical, employment-related or recreational services, or to transport the group as a whole to access such services in the community, thereby reducing the chances for meaningful interaction with the community.

Group homes are often a model which links together the disability supports a person requires with a particular stock of housing, thereby restricting people’s choices about where they will live. They can only access supports they require by submitting themselves to a service provider who owns or operates certain housing stock. People with disabilities do not require special housing stock; they require supports which they can take into the housing market to access rental or other housing tenure just like other people.

76. See for example Academic Network of European Disability Experts (ANED) 2009 report (op cit).

77. CRPD, Article 8(2)(ii).

By how services are provided

The way all services revolving around the right to live in the community are provided – not only residential services – also affects the degree to which one is included and participates in the community.

For example, individuals may be required to accept a general “package” of services that include residence, personal assistance and supported employment, all under one provider, rather than be able to choose a particular provider or type of service, or even if they desire that service. This bundling of services requires the individual to forfeit choice and control and inhibits inclusion by fostering dependence and creating a disincentive to attain higher levels of self-sufficiency. The bundling of services can also be misused as a linchpin to force certain services, or even treatment, on the individual. The penalty for refusing to accept one aspect of the bundled services is the loss of all services. Finally, service bundling can inhibit competition among providers, which arguably compromises quality and negates choice for the customers.

A system that shepherds people with disabilities to different segregated locations in the community, e.g., a sheltered workshop, day treatment centre, or rehabilitation centre, also inhibits community participation and inclusion. Spending months or years in such closed circuits impedes prospects for exiting the system, exercising more choice, and increasing opportunities for true community inclusion.

Appendix: Indicators and guiding questions

This Appendix focuses on monitoring implementation of the right to live in the community. Since the transition from various forms of segregation that constitute a violation of this right to successful implementation will have to happen in processes that may take years to complete, those engaged with monitoring implementation must have tools to assess whether the transition is advancing satisfactorily.

The following indicators and guidance questions are not exhaustive – a full assessment tool would require a team and comprehensive multi-disciplinary process to compose. Neither are they a blueprint for implementing the right. Rather, they are suggestions for benchmarks to ensure that implementation processes reflect the underpinning principles of the right to live in the community.

Part A of this Appendix (Sections 1 to 3) provides background to the indicators and guiding questions. It addresses the importance of monitoring, and lists the various stakeholders who may be involved in monitoring, to whom the indicators and guiding questions can be of help, as well as the diverse range of people with disabilities they target.

Part B (Sections 4 to 6) includes the actual indicators and guiding questions which emanate from the principles addressed in the Issue Paper. The indicators and guiding questions proposed aim to provide a tool for evaluating:

- Whether inclusion in the community is being implemented in a given society (Section 4, corresponding to Chapter 3.1. above).
- Whether the right to live in the community is being violated (Section 5, corresponding to Chapter 3.2 above).
- Whether a transition is taking place from violation of this right towards implementation (Section 6).

Part A: Background

1. Monitoring implementation

Monitoring progress towards implementing the right to live independently and be included in the community for people with disabilities is crucial. Through such monitoring, governmental and non-governmental entities can track changes over time and develop or adjust reform strategies. Legislative, administrative and policy measures to ensure that this human right is respected, protected, and fulfilled can be recommended. The public can be informed and empowered to take action and hold governments to account.

Monitoring implementation is of prime importance for domestic audiences. Reports, with clear recommendations, can be sent to central government ministries, local governments, and parliamentarians. National human rights institutions, and civil society organisations, particularly people with disabilities and their representative organisations, all have a stake in ensuring full and effective implementation and should invariably be involved in carrying out such monitoring.

Monitoring also can be used internationally. Reports can be sent to the UN Committee on the Rights of Persons with Disabilities, which assesses a State Party's compliance with its obligations under the CRPD. The Committee's concluding observations can highlight key issues of concern and recommendations for follow-up. Remedies can be sought for non-compliance from the Committee through the individual complaints mechanism established by the Optional Protocol to the CRPD. These indicators can also be used to provide information to other mechanisms, such as other UN treaty bodies, and regional mechanisms, such as the European Committee on Social Rights, which monitors compliance with the European Social Charter.

Monitoring is successful only if it is carried out credibly and independently, if results are disseminated, action is demanded, and steps are taken by those in positions to implement changes toward fulfilling the right to community inclusion. Particularly, those carrying out the monitoring should alert relevant government officials, national human rights institutions, as well as civil society organisations, of monitoring results. In some contexts, the media can be instrumental in enabling the general public to become aware of these issues and call for change.

2. Key stakeholders

The indicators and guiding questions are written to enable specific groups of people to carry out monitoring. These include, but are not limited to:

1. people with disabilities, their representative organisations, and other non-governmental organisations;
2. international monitoring bodies such as the UN Committee on the Rights of Persons with Disabilities, and regional mechanisms such as the European Committee on the Prevention of Torture and European Committee on Social Rights. The indicators could be useful for data collection and research bodies such as the EU Agency for Fundamental Rights;
3. independent monitoring bodies, including those designated to carry out monitoring of CRPD implementation under Article 33(2) of the CRPD;

4. national preventive mechanisms established under the Optional Protocol to the UN Convention against Torture, and other independent bodies carrying out inspections of human rights in places of detention;
5. academic researchers;
6. parliamentarians;
7. governmental bodies and agencies, including focal point(s) established under Article 33(1) of the CRPD, who are responsible for coordinating implementation across government, and people in specific governmental ministries or departments responsible for implementing the right to independent living and being included in the community.

3. Addressing a diverse range of people with disabilities

The indicators and guidance questions aim to capture the phenomenon of segregation, including institutionalisation, as applied to all people with disabilities, including those groups particularly exposed to segregation. These include:

- people with intellectual disabilities;
- people with psychosocial disabilities;
- people with physical or sensory disabilities and high support needs or ongoing medical needs;
- people with dual diagnosis (intellectual and psychosocial disabilities);
- people with other forms of multiple disabilities.

Other marginalised groups that would benefit from being included in the application of the indicators and guiding questions for implementation include older people; people of ethnic, religious or linguistic minorities; women; children; immigrants; refugees and asylum seekers; LGBT people; people who are homeless; and substance users.

Part B: Indicators and guiding questions

4. What constitutes implementation

The following indicators and guiding questions can be used to monitor whether the vision of the right to live in the community is being incorporated in implementation. They follow the core components of Article 19 relating to choice, access to individualised support services, and equal availability and responsiveness of community services and facilities for the general public.

Identifying how people without disabilities live in the community

1. What is the range of ways that people without disabilities live in the community in a given country/region:
 - a. In general, do people live as part of the extended family, or do they live alone or with a partner or a flat-mate once they gain adulthood?
 - b. If people share homes, how many generally live together – would the number exceed three to four people?
 - c. Do people generally leave their homes every day to go to a workplace?
 - d. Is foster care considered an option for adults without disabilities?

This information may be found in academic research such as sociology and social policy, from national statistics agencies, from NGO reports, and so on. There may be considerable variation within the same jurisdiction.

Schemes facilitating inclusion

2. Are living arrangements and supports provided in a way which enables individuals to use the general public services? For example, is support provided, where necessary, to reach general medical or recreational services, rather than having them brought into the living setting and provided in a collective manner?

Access to individualised support services

3. What are the types of services available that support living independently in the community? These could be:
 - a. budgets allocated to individuals in need of support services (personal budgets)
 - b. personal assistance
 - i. Is personal assistance allocated as a cash payment, a voucher that can be used to buy a service, or as the service itself (for example entitlement to a number of hours per week)?
 - ii. In what areas of life is personal assistance offered, i.e., for which activities (daily living, housekeeping, financial activities, advocacy, recreation, employment, education)?
 - c. assistance to individuals in accessing funding and support services, which are independent of government
 - d. support to families; is it in the form of:
 - i. benefits

- ii. support by a family member which is properly remunerated
 - iii. surrounding support services (such as day care)
 - iv. early childhood support
 - v. respite care
- e. residential services (see more below)
- f. surrounding support:
- i. equipment and assistive devices to aid mobility, communication, and independent living
 - ii. accommodations in homes/workplaces
 - iii. assistance in finding and maintaining employment, and support within the workplace
4. What is the scope of the supports?
- Who is entitled to supports?
 - What is the scope of the entitlement? Does the entitlement (e.g., budget, number of hours, type of services covered) enable people with high support needs to live in the community?
5. What are the types of entitlement?
- Are they at the discretion of the authorities?
 - Are they dependent on available funds?
 - Is there a statutory basis for the entitlement? In other words, can the person claim the entitlement in law through litigation?
6. What are the criteria for entitlement?
- Are the criteria needs-based or diagnosis-based?
 - Is there transparency in the application of criteria for entitlement and in the rules governing entitlement allocation?
7. Is there equality in access?
- Is access equal regardless of geographic location?
 - Is access equal for women and men?
 - Is access equal regardless of disability?
 - Is access equal for minority and migrant populations? Orphans?

8. How portable and transferable are entitlements?
 - Are individuals able to “carry” the entitlement with them if they move residence or locality?

Access to justice

9. Does a person with disability have direct access to redress mechanisms around living in the community?
 - Are these mechanisms independent of another person (such as a relative or guardian, as long as guardianship prevails)? This should cover the legal authority to initiate and conduct legal proceedings and challenge rights violations before courts and non-judicial authorities (local government, equality bodies, etc.).

Legal capacity

10. Is a person with disability recognised as having the legal capacity to make his/her own choices (as per CRPD Article 12(2)), including with regard to one’s living setting or is a guardian or someone other than the individual authorised to agree on placement in an institution or the types of services and supports the person with a disability receives?
11. Is a person with disability enabled to enter the necessary contracts and agreements for disability-related supports, access to credit to purchase housing, or rental or other housing agreements?
12. Does a person with disability have access to support to enable them to make decisions about where and with whom to live or what support services to access (as per CRPD Article 12(3))?

Choice: Self-directed support

13. Are individuals provided with the opportunity to:
 - recruit and manage staff providing personal assistance?
 - determine the activities for which support is needed?
 - determine how the budget for services and supports will be used?
 - choose types of equipment and adaptations to best meet their needs?
14. What type of input can individuals provide where services are provided by agencies?
15. Are service provision agencies consumer-led? Are they run by people with disabilities? Do people with disabilities have a role in their operation or oversight?

Equal availability and responsiveness of mainstream community services

The following questions aim to expose the extent to which mainstream services are inclusive, while not over-broadening the discussion towards monitoring of the implementation of all other rights guaranteed by the CRPD with links to the right to live in the community.

16. If any type of social support is provided to the general community (support to families, day care, housing support, assistance in finding work, vocational training, etc.), do people with disabilities also have access to these supports?
 - a. Are the services physically accessible?
 - b. Are the services and supports accommodating of people with various disabilities and needs?
 - c. Are they advertised as catering to people with disabilities as well?
 - d. Do any policies establish barriers to the ability to access services of people with disabilities?
 - e. Are staff operating the services trained or supported in providing the services to people with disabilities?

The following questions are particularly relevant in resource-scarce settings, or where individualised supports are not yet in place. The questions help to expose types of services relating to various areas of life available to the public, which can be made available to people with disabilities in a way which will enable their inclusion in society.

- f. Is a concerted effort being made by the central government, local governments, and various community workers to strengthen the message to the public about the importance of including people with disabilities in all realms of life, as well as the relevant international undertakings of the authorities? Is the message being brought to families about the need to properly assess the needs of their family members, and the importance of including their family members in family and community life, with the necessary accommodations?
- g. Do families receive support, either in benefits or in training, in how to enable their family members with disabilities to live to their full potential and be included within the community at the various life-stages (as children, young adults, adults, and as older people) and areas of life (health, education, employment, recreation, family life)?
- h. Where childcare is provided, is it available to children with disabilities on an equal basis with others?

- i.* Are children with disabilities enabled to attend inclusive educational settings, or are they denied real choice and as a result remain secluded in their homes or in segregated/special schools? What steps are taken to decrease the number of children with disabilities not attending school, and increase the number of those attending mainstream primary and secondary schools?
 - j.* Is any support provided to young people with disabilities in acquiring skills to join the labour market, finding jobs, conducting a meaningful everyday life?
 - k.* Are schools offering vocational training, and are vocational training centres aware of the need to provide services to people with disabilities as well? Are they encouraged to do so, and are they provided with training and support to do so?
 - l.* Do people with disabilities have access to vocational training?
 - m.* Do work and training centres for people with disabilities encourage inclusion in the regular work force, rather than only in separate workshops?
 - Do they train people with disabilities for work in the open labour market?
 - Do they help identify job openings that may be relevant to the individuals they are training?
 - Do they take steps to raise awareness of employers to the importance and possibility of including employees with disabilities?
 - Do they provide on-site support to people with disabilities and to employers with a view to helping people with disabilities to find and maintain a job in the open labour market?
17. Do community centres reach out to people with disabilities and their families? Are they accessible and are the services they provide inclusive of people with disabilities?
18. Are health clinics accessible to people with disabilities?
- a.* Is the staff trained to communicate with and provide services to people with various types of disabilities?
 - b.* Do they reach out to families with people with disabilities and encourage making use of available services for ongoing health assessment and maintenance for family members with disabilities?

19. Are welfare and justice and law enforcement agencies aware of the needs of people with disabilities?
 - a. Do they reach out to people with disabilities, families, schools and community workers, to ensure adequate reporting mechanisms in cases of neglect or abuse?
 - b. Do they encourage reporting on these issues? Have they acquired the capacity to address special communicational needs of people with disabilities that would enable them to tell their story?
20. Wherever the local government provides services or supports to the general public, do these services target people with disabilities as well and are they made accessible?
 - a. Where the local government provides funding for services to the general public, such as supporting community centres, job training centres, or health facilities, does it require that they target people with disabilities as well and does it provide training and support for that purpose?

5. Violations of the right to live in the community

The following indicators and guiding questions can be used to monitor to what extent the right to live in the community is violated, by various forms of segregation – whether through institutionalisation or segregation within the community.

Where are people with disabilities living?

21. How many people, with what types of disabilities, live in institutions**, compared with how many live outside of institutions?
22. How many people live within each of the institutions?
23. Are there limits/caps on new admissions to institutions?

Collecting basic facts in a way which can identify a trend over time

24. Set of quantitative data:
 - Number of institutions**
 - Total number of residents within institutions
 - Places available, and occupied, within each institution
 - Number of new admissions to institutions

- Number of transitions to the community**

All of this data should be captured in the current calendar year, as well as for previous years. The importance of capturing historical data cannot be overstated, as trends over time will reveal progress or regress. The length of time to be examined would range between a number of years and a decade, depending, among others, on available data, and when relevant policy and legislative landmarks were introduced (for example, when disability rights legislation took effect). Once historical data has been collected, increases and decreases can be articulated as follows:

- Increase or decrease in types of community-based services and supports
- Increase or decrease in governments' or organisations' capacity to provide community-based services
- Increase or decrease in types and size of entitlements, and in the number of beneficiaries of support services in the community
- Funding of institutions versus community frameworks

** Attention should be given to ensure that living settings geographically placed in the community, but that do not enable the participation in society or the exercise of choice, are captured within the category of “institutions.” For example: homes for older people, nursing homes, social care homes, psychiatric hospitals or departments, rehabilitation centres, healing camps, orphanages, and general social welfare institutions.

Segregated settings within the community

25. How many individuals reside together in settings presented as community-based ones for which support is provided?
26. Where are the settings located – on the grounds of an institution, within a neighbourhood, on the outskirts of town, in a remote part of the countryside?
27. Are the homes clustered, for example, is there an apartment complex exclusively for people with disabilities, a number of apartments in one building, or are they scattered throughout the neighbourhood or neighbourhoods?

Distinctions, exclusions, restrictions to the right to live in the community

28. Are any groups excluded or at risk of exclusion from policies enabling living in the community? Are some barred from entitlements and support provided to live in the community?

29. Do certain criteria for eligibility for support in the community de facto disqualify people with certain disabilities, even if not mentioned by name?

These “groups” may include:

- people with intellectual disabilities
- people with psychosocial disabilities
- people with physical or sensory disabilities and high support needs or ongoing medical needs
- people with dual diagnosis (intellectual and psychosocial disabilities)
- people with other forms of multiple disabilities
- older people
- people belonging to minority/ethnic groups
- girls and women
- children
- LGBT people
- people who have lost family ties
- people who are homeless
- other people who may be in situations of vulnerability

30. Are people with disabilities referred to living arrangements that are not a common setting for the general society, such as adults with disabilities being referred to foster homes?

Identifying the process which leads to placement in institutions versus community settings

31. Who determines the type of placement, according to what legal criteria and process? Is there an appeal process?
32. What choices are individuals and families presented with? For example, are they provided with a realisable option in the community? If so, what is the average waiting time? What is the average waiting time for placement within an institution, and what does that mean for the individual or the family?

Segregation through the way services are provided

33. Is the entitlement for bundled services that make the receipt of one type of service conditional upon receiving other services?

- a. In the area of housing: Do support services come part-and-parcel of a certain type of residence?
- b. Generally: Are individuals required to accept a general “package” of services that include residence, personal assistance and supported employment, or a combination, all under one provider, rather than be able to choose a particular provider or type of service?
- c. Is undergoing treatment a condition for receipt of support services and is there a penalty of loss of services upon refusing treatment?

Access to information regarding available community alternatives and support services

34. What information are individuals and family members presented with regarding options for living frameworks and support services in the community? Is this information available in alternative formats, for instance, in Braille or in plain language?
35. Is information regarding community-based options withheld from people with certain types of disability because they are not perceived as candidates?

Financing

36. What is the amount of government funding and private funding for institutions?
37. What is the amount of government funding and private funding for community-based support services?
38. Are international funding sources going towards building, expanding, or refurbishing institutions, or to developing community support services? For example:
 - international development agencies
 - funding by foreign governments
 - European Union funds
 - World Bank
 - private funding sources
39. What is the proportion of funding towards institutions versus funding towards community services and frameworks?
40. What is the budget allocation per individual in each option?

41. To what extent are financing and budget allocations geared to support maximum individualisation of services and control over the services by the individual?
42. What are the overt and covert incentives and disincentives embedded in each option? (for example: tax incentives or allocation of public funds towards one option over the other, directors of institutions being the guardian of residents and able to control and use this money).

6. Moving from violation to implementation

The following indicators and guiding questions can be used to monitor the transition from violation to implementation. These address whether laws and policies are in place to facilitate such a transition, as well as monitoring schemes to guarantee implementation.

Public commitment

43. Is there any outward expression that would demonstrate that living in the community is a priority for the government? Has the government publicly recognised the right of all people with disabilities to live in the community? Has it made a public commitment to enable inclusion in the community? This could take the form of a special declaration, an action plan, a designation of a governmental task force, and the like.
44. Are there limits to the public commitment, are any groups excluded?

Plans for transition

45. Does a plan for development of services in the community exist?
46. Is there a plan with a timeline and concrete, measurable steps for deinstitutionalisation, linked with a plan for developing services in the community and showing how individuals once institutionalised will receive a community-based response and the type of response?
47. Does a plan exist to ensure the right to equal recognition before the law (legal capacity), with appropriate supports, where desired, to enable people to live independently and be included in the community?
48. Does the plan address the specifics of where individuals will be placed when they transition out of the institution?
49. What is the range of community support services that are being offered in the plan?
50. Does the plan emphasise those groups within the disabilities community most at risk of segregation, such as people with multiple disabilities or those who require more intensive supports, people with intellectual disabilities

or people with psycho-social disabilities, children, older people, people from racial and ethnic minorities and LGBT people?

This information should be disaggregated by various types of institutions and disabilities.

Development of support services in the community

51. Is there an effective process for developing community-based options, such as public tenders? Are there appropriate incentives?
52. If a rate is provided to operators to provide services – is it realistic? Does it enable operators to provide services of reasonable quality?

Creating an enabling legal framework

53. Does the law regulate the following issues, essential to pursuing equality and non-discrimination?
 - a.* a legal prohibition on institutionalisation (at the very least on new admissions);
 - b.* the right to receive support in an environment conducive to full and equal participation and inclusion in society;
 - c.* upholding of full legal capacity and access to support to enable decision-making by the individual;
 - d.* establishing that a decision on living in a segregated setting cannot be a decision undertaken by anyone other than the individual;
 - e.* a level of support as an entitlement, below which one's dignity and ability to be included in the community would be jeopardised, and which may therefore not be compromised;
 - f.* the right to access advocacy support in order to empower people with disabilities to broker and negotiate inclusion, as well as to participate in designing laws and policies on these issues and implementing, monitoring and evaluating them.

Involvement of people with disabilities in development, implementation and monitoring of laws and policies

54. How are people with disabilities consulted and involved in –
 - developing a deinstitutionalisation plan
 - implementing such a plan
 - monitoring the implementation of such a plan
 - crafting a plan and developing services and supports in the community

Recognising the right to live in the community is about enabling people to live their lives to their fullest within society and access the public sphere. A precondition for anyone to enjoy all their human rights, this right is taken for granted by the majority of the population, but is often denied to persons with disabilities, who are instead placed in segregated institutions or in settings which isolate them from the rest of the community.

This Issue Paper describes the challenges faced by Council of Europe member states in complying with this right. It traces the right of people with disabilities to live independently and be included in the community to its origins in the most fundamental human rights standards both within the Council of Europe and United Nations systems. The paper draws on Article 19 of the UN Convention on the Rights of Persons with Disabilities to identify the various forms that violations of this right can take, and provides guidance for community-based responses governed by choice, in order to achieve inclusion and participation. The paper shows the link between the right to live in the community and other rights, notably the right to equal recognition before the law (legal capacity). The Issue Paper ends with a sample of indicators and guidance questions to assess the transition from violation to implementation of the right to live in the community.

The Commissioner's recommendations on the right to live independently and be included in the community are published at the beginning of the document.

- implementing such a plan and running such services and supports
- monitoring the implementation of such a plan

Monitoring in the interim, until institutions are phased out

55. Is there an independent national monitoring mechanism which effectively monitors whether the human rights of residents in institutions are upheld?
56. Has the country ratified the UN Convention against Torture and its Optional Protocol?
57. Has it set up a “national preventive mechanism”?
58. Are visits carried out methodologically by an independent mechanism, are reports issued, and are recommendations followed up?

Monitoring of community-based schemes and support

59. Are community-based schemes and supports monitored to ensure quality and prevent abuse? For example:
 - a. Are licensing of service providers and their ongoing operations regulated? Is training of personnel in provision of services to consumers required?
 - b. Are quality-control standards applied to the provision of services?
60. Is the monitoring being carried out by an independent body (per CRPD Article 33(2))?
61. To what extent are people with disabilities and their representative organisations part of this monitoring (per Article 33(3) of the CRPD)?

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