

A Community for All: Implementing Article 19

A Guide for Monitoring Progress on the
Implementation of Article 19 of the
Convention on the Rights of Persons with Disabilities

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Chapter 1: Introduction

Purpose and Scope of this Guide

This Guide aims to show how the Convention on the Rights of Persons with Disabilities (CRPD) can be used to promote the right of people with disabilities to live and participate in the community as equal citizens. Its primary focus is Article 19 of the CRPD (Living independently and being included in the community), which provides that people with disabilities have the right to live in the community, with the same choices as others.¹

By considering the obligations of States under Article 19 and other relevant rights under the CRPD, this Guide reinforces the urgent need for action to end the institutionalization of people with disabilities. This requires the current system of institutional services in many countries that have ratified the CRPD to be replaced with appropriate community-based services that promote social inclusion. Governments of countries in which people with disabilities continue to be institutionalized must take such action if they are to comply with their obligations under the CRPD.

This Guide identifies the main areas of work that governments will need to consider when planning how they are to meet their obligations under Article 19. These areas of work are based on relevant CRPD rights and existing commentary on the scope and potential impact of these rights.² It includes checklists and questions on areas of key importance. These can be used by organizations of people with disabilities, human rights organizations, policymakers, and others advocating for reform in this area, to identify what work is necessary for the implementation of Article 19 and how to ensure that civil society and people with disabilities are actively engaged in this process.

Community Living and the Convention on the Rights of Persons with Disabilities

The CRPD is the first international human rights treaty to expressly recognize the right of all people with disabilities to live and participate in the community as equal citizens. By ratifying the CRPD, States have made a commitment to ensuring that people with disabilities can live, and participate fully, in their communities. This is made explicit in Article 19, which requires States to take appropriate measures to facilitate “full inclusion and participation in the community” of persons with disabilities.

Governments are therefore required not only to take action to ensure that people with disabilities can live in the community, but also to *provide the support and structures that enable people with disabilities to engage in community life*. The term “community living” describes the right of people with disabilities to live in the community and receive the support that they need to participate in society as equal citizens. This will encompass a range of services and supports such as housing (including supported housing), care in the family home, social work support, and supported employment, as well as access to mainstream services such as health care.

¹ A shorter version of this Guide, *A Community for All Checklist*, is available at: www.soros.org/health/crpd.

² The guide would thus need to be read in accordance with any future guidance issued by the Committee on the CRPD issues on Article 19 and/or related CRPD articles.

The Institutionalization of People with Disabilities: Contrary to the CRPD

Although it is difficult to obtain reliable statistics, in part because governments keep inadequate records, the available data suggests that the practice of institutionalizing people with disabilities, often for life, is still prevalent in many parts of the world. A European Commission-funded study of European Union Member States and Turkey, *Deinstitutionalisation and Community Living: Outcomes and Costs* (“the DECLOC report”), found that there are almost 1.2 million people with disabilities living in institutions in these countries. The two largest groups affected are people with mental health problems and people with intellectual disabilities.³

The living conditions in such institutions are often extremely poor, the regimes are rigid and impersonal, there are little to no therapeutic activities, and residents are subject to physical and sexual abuse. In addition, residents have little or no contact with the outside world. These amount to serious human rights violations.⁴ An instinctive and common response by governments to such concerns is to attempt to improve living conditions, principally by renovating institutions. This may improve the physical environment, but it does nothing to address the fundamental issue that the segregation of individuals from society is in itself a serious violation of their fundamental human rights. This is because forcing people with disabilities to live in institutions, thereby preventing them from developing and maintaining relationships with their family, friends and the wider community, is in direct conflict with the rights set out in Article 19.

The Need for Community-based Alternatives to Institutional Care

There are many reasons why institutionalization of people with disabilities persists, but a primary one is the severe lack of support in local communities that would enable people to live in their own homes. This is perpetuated by a lack of commitment on the part of governments to take action to transform the system of institutional care and support the development of a range of services that would enable all people with disabilities to live in their communities. This lack of commitment persists despite clear evidence that outcomes for people with disabilities are significantly better when they have the opportunity to live as equal citizens.⁵

Although many governments have policies on paper that seek to promote the human rights and social inclusion of persons with disabilities, progress in developing alternatives to institutionalization is painfully slow. In fact, concerns have been raised that in some countries,

³ Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent; p. 97 (further referred to as ‘the DECLOC report’), page 29

⁴ See, for example, Interim Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 2008 A/63/175 and comments by the Council of Europe Commissioner for Human Rights, Thomas Hammarberg in ‘Inhuman treatment of persons with disabilities in institutions’ posted 21 October 2010 http://commissioner.cws.coe.int/tiki-view_blog.php?blogId=1&bl=y&offset=30

⁵ The DECLOC Report, page 3

European Union funding has been used to maintain the system of institutional care by, for example, building new institutions.⁶

The lack of community-based services also impacts upon people with disabilities who remain with their family. Often they fare little better than those in institutions because their relatives are likely to have little to no support in caring for them. Furthermore, due to the widespread and pervasive stigma attached to disability generally, and in particular to mental health problems and intellectual disabilities, families may seek to hide the very existence of their disabled relative. Like their peers living in institutions, they are all too often marginalized, excluded and forgotten.

Unless and until action is taken to develop community-based alternatives, including the provision of support to people with disabilities and their families, people with disabilities will continue to be placed in institutions or isolated in their own homes. Accordingly, the emphasis of community-based services must be to enable people with disabilities to participate in community life as equal members of society.

In countries where the institutionalization of people with disabilities is currently the predominant form of care, the development of community based services to replace institutional care will be central to meeting their obligations under Article 19.

⁶ See for example, European Coalition for Community Living, Wasted time, wasted money, wasted lives – a wasted opportunity? A focus report on how the current use of Structural Funds perpetuates the social exclusion of disabled people by failing to support the transition from institutional care to community-based services, March 2010, available at: www.community-living.info/.

Chapter 2: Community Living and the Convention on the Rights of Persons with Disabilities

This chapter provides an overview of the Convention on the Rights of Persons with Disabilities and explains its significance in promoting the right of people with disabilities to live and participate in society as equal citizens (the right to community living).

Convention on the Rights of Persons with Disabilities: Overview

The CRPD sets out a wide range of rights that address all aspects of life, such as respect for home and the family, education, employment, health, participation in political and public life, participation in cultural life, recreation, leisure and sport, the right to life, freedom from torture or cruel, inhuman or degrading treatment or punishment, and the right to equal protection and equal benefit of the law.

States may also ratify the Optional Protocol to the CRPD which allows the Committee on the Rights of Persons with Disabilities (“the CRPD Committee”) to examine individual complaints and to conduct inquiries in relation to that State. The CRPD and its Optional Protocol can be found on the United Nations Enable website at: <http://www.un.org/disabilities/>.

Ratifications of the CRPD

The CRPD came into force in May 2008. To date:

- 106 States have ratified the CRPD (those that have ratified the CRPD are referred to as “States Parties”) while 153 States have signed the CRPD.
- 63 States have ratified the Optional Protocol.⁷

The CRPD was ratified by the European Union on December 23, 2010. It is the first international human rights convention to be ratified by the European Union.

Monitoring mechanisms under the CRPD⁸

The CRPD requires monitoring at both international and national levels.

- **International:** States must submit periodic reports to the CRPD Committee detailing their progress in implementing the CRPD. They must provide “a comprehensive report on the measures taken to give effect to its obligations” under the CRPD (Article 35).
- **National:** States must establish a range of mechanisms to oversee the implementation of the CRPD (Article 33). The CRPD is the first human rights treaty to contain such detailed provisions on national monitoring and implementation frameworks.

⁷ As at 30th November 2011. Updates on the numbers of signatories and ratifications are provided at the United Nations website, Enable: <http://www.un.org/disabilities/>

⁸ Further information on the monitoring of the CRPD is given in Annex 1

The Right to Community Living and the CRPD

The right to live and participate in the community is integral to the CRPD. In addition to being incorporated into a specific right under Article 19, the themes of living in the community, inclusion, and participation run throughout the text of the CRPD. For example, one of the general principles of the CRPD is the “full and effective participation and inclusion in society” (see Article 3). Article 26 (Habilitation and rehabilitation) focuses on supporting people with disabilities to attain and maintain “full inclusion and participation in all aspects of life.”

Article 19 and Community Living

Article 19 is very broad in scope. It provides “the equal right of all persons with disabilities to live in the community, with choices equal to others.” States are required to “take effective and appropriate measures to facilitate the right to live in the community and to promote “full inclusion and participation in the community.” This right applies to all persons with disabilities, regardless of the degree of the disability or the level of support necessary. The full text of Article 19 is set out in the box below.

Article 19 (Living Independently and Being Included in the Community)

State 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:

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;

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;

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 therefore requires States to:

- Recognize the right of people with disabilities to live in the community,
- Take effective and appropriate measures to facilitate their full enjoyment of that right, with choices equal to others, and
- Take effective and appropriate measures to facilitate people with disabilities’ full participation and inclusion in the community.

Article 19 also provides an illustrative but non-exhaustive list of the “effective and appropriate measures” States are required to take. Specifically, as part of their efforts to realize these rights, States are required to ensure that people with disabilities have:

- **Choice of residence:** *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 (Article 19(a))*

In many countries of Central and Eastern Europe and the former Soviet Union, a major barrier to the exercise of this right is the guardianship system that prevents people from making personal decisions in a wide range of areas such as employment, marriage, voting, and where to live. Accordingly, this aspect of Article 19 will need to be considered alongside the work to implement Article 12 (Equal recognition before the law) of the CRPD, which requires States to recognize that people with disabilities “enjoy legal capacity on an equal basis with others” and that they “take appropriate measures to provide access by persons with disabilities to the support that they may require in exercising their legal capacity.”

The Office of the High Commissioner for Human Rights emphasizes that guardianships laws should be reviewed as a matter of priority and that subsequent legal reforms introduce:

“...legal recognition of the right of persons with disabilities to self determination; of alternative and augmentative communication; of supported decision-making as the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters; and the establishment of regulations clarifying the legal responsibilities of supporters and their liability.”⁹

- **Access to a range of community support services:** *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 (Article 19(b))*

The development of community-based services as alternatives to institutional care is crucial to States’ compliance with Article 19. As noted above, without such services people with disabilities have no real choice about their place of residence. This aspect of Article 19 links with Article 26 which requires States to facilitate the provision of services and programs to support participation and inclusion in the community.

- **Equal access to mainstream community services:** *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(c))*

The right of equal access to mainstream community services derives from the principle of non-discrimination and is also central to the enjoyment of the right choice of residence. For many people with disabilities, ensuring that they can enjoy their right to equal access to

⁹ Thematic study by 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, January 2009, A/HRC/10/48, para. 45 (Referred to as ‘A/HRC/10/48’)

mainstream community services will require that they receive support to do so. This aspect of Article 19 links to Article 9 (Accessibility) which requires States to take measures to ensure that people with disabilities have access, “on an equal basis with others, to the physical environment, to transportation, to information and communications technologies and systems, and to other facilities and services open, or provided to the public.”

The concept of “reasonable accommodation” will be relevant to this aspect of Article 19. The *Handbook for Parliamentarians - From Exclusion to Equality: Realizing the Rights of Persons with Disabilities*¹⁰ notes that under the CRPD “a failure to afford a person ‘reasonable accommodation’ amounts to a discrimination on the basis of disability.” It explains:

“To afford a person ‘reasonable accommodation’ means for example, making adaptations to the organization of a work environment, an educational establishment, a health care facility or transport service in order to remove the barriers that prevent a person with a disability from participating in an activity or receiving services on an equal basis with others.”¹¹

Article 19 and the Closure of Long-Stay Institutions

Although Article 19 makes no specific reference to the need to close long-stay institutions (i.e., deinstitutionalization), its provisions make clear that their closure is required, together with the development of community-based alternatives.

This is both because the emphasis of Article 19 (and indeed the whole Convention) is on full inclusion and participation in the community and because the closure of long-stay institutions is necessary for the enjoyment of Article 19. The requirement of Article 19 that States ensure that persons with disabilities have access to community services that support their social inclusion and “prevent isolation or segregation from the community” simply cannot be achieved if governments continue to place people with disabilities in institutions, preventing them from developing and maintaining relationships with their family, friends, and the wider community.

Thus, irrespective of the quality of care in institutions, the practice of isolating and segregating people with disabilities in long stay institutions is in itself a violation of their human rights under Article 19. It will also engage other rights such as Article 14 (Liberty and security of the person), Article 22 (Respect for privacy) and Article 23 (Respect for home and the family).

When developing community based alternatives to institutionalization, governments must ensure that such services are designed to enable each person to participate in community life. As the Office of the High Commissioner on Human Rights observes, deinstitutionalization is “necessary but not sufficient to achieve the goal of independent living.” It adds that it will be necessary for legislation to establish independent living as a legal right and that “independent living support should be provided and arranged on the basis of the individual’s own choices and aspirations, in line with the principles of the Convention.”¹²

¹⁰ United Nations, 2007

¹¹ Page 60

¹² A/HRC/10/48, para. 51

Chapter 3: Key Issues for the Implementation of the Convention on the Rights of Persons with Disabilities

This chapter highlights five issues that are likely to be significant to the implementation of the CRPD and will be important factors when considering whether governments are complying with their obligations under the CRPD as a whole. These initial steps will also be essential to the implementation of Article 19 (steps specific to Article 19 are considered in Chapter 4).

By ratifying the CRPD, States have committed to ensuring that their citizens can exercise the rights set out in the CRPD.¹³ Governments will need to consider their laws, policies and practices as well as their financial and strategic planning (such as how they allocate their budgets) to ensure that the obligations set out in the CRPD are reflected in their “national legal framework, development planning and budgeting, and in related policies.”¹⁴

States Parties are required to provide periodic reports on their progress in implementing the CRPD to the CRPD Committee. To assist States Parties, the CRPD Committee has issued guidelines advising on the form and content of these reports and included the expectation that States Parties provide information on their progress in realizing the rights under the CRPD.

While ratification provides a very clear public commitment on the part of the government to protecting and promoting the rights of people with disabilities, it is often not followed by concrete implementation plans. Civil society, including organizations of persons with disabilities, have an important role in ensuring that governments take concrete and targeted steps to meet their obligations under the CRPD. The monitoring of the government’s compliance with the CRPD will be an on-going process (a summary of the international and national monitoring mechanisms for the CRPD is provided in Annex 1).

This chapter considers the following five areas that are likely to be significant to the effective implementation of the CRPD:

1. The status of the CRPD upon ratification
2. Raising awareness about the CRPD
3. Harmonizing national law and policy with the CRPD
4. National monitoring
5. Participation of people with disabilities

¹³ Information for advocates working in countries which have signed, but not as yet ratified the CRPD, is provided in Annex 2

¹⁴ Handbook for Parliamentarians, page 7

The Status of the CRPD upon Ratification

Two preliminary issues to consider are whether the government has made a reservation to the CRPD and if the CRPD has become part of national law upon ratification.

Reservations to the CRPD

Although not encouraged to do so, some States have made reservations to the CRPD.¹⁵ The Office of the High Commissioner for Human Rights recommends that States should carefully evaluate whether to lodge reservations, noting that human rights treaty bodies:

“...have consistently expressed the view that reservations might have the effect of diminishing the scope of protection afforded by treaties.”¹⁶

If any reservation has been made, civil society organizations can seek clarification as to why this was considered necessary. The CRPD Committee’s guidelines to States on the form and content of their periodic reports advises that any reservation or declaration relating to any article of the CRPD “should be explained and its continued existence clarified.”¹⁷

Status in National (Domestic) Law

In some countries ratification of the CRPD means that it becomes part of national law, but in other countries it would need to be incorporated into domestic law through domestic legislation. This is because some States adhere to a “monist” approach (such as Croatia, Hungary, and Slovenia) so that treaty provisions become part of domestic law on ratification, whereas in dualist legal systems (such as the United Kingdom) legislation is needed to make the treaty part of UK law.

In States where the CRPD is not incorporated into domestic law, governments must still take action to comply with the CRPD, including by amending national laws and policies, but individuals will not be able to take legal action against the government simply on the basis that their rights under the CRPD have been breached. However, in such cases it might be possible for the CRPD to be used to support the complaint, with the courts using the CRPD as an “interpretive tool” by referring to rights under the CRPD when deciding the meaning of relevant national law.

The Office of the High Commissioner for Human Rights recommends that the CRPD be incorporated into national law as this “realizes the full potential of the treaty and results in enhanced protection.”¹⁸

¹⁵ The Handbook for Parliamentarians, page 44 explains “A reservation is a statement that purports to exclude or modify the legal effect of a treaty provision with regard to the State or regional integration organization concerned.” However reservations that are incompatible with the object and purpose of the CRPD are not permitted (Article 46).

¹⁶ A/HRC/10/48 para. 20

¹⁷ CRPD/C/2/3, para. A.10

¹⁸ A/HRC/10/48, para. 70

Raising Awareness about the CRPD

Article 8 of the CRPD requires States to take “immediate, effective and appropriate measures” to raise awareness about persons with disabilities, including “to foster respect for the rights and dignity of persons with disabilities.” Some of the measures that the CRPD Committee expects governments to address in their periodic reports to the Committee include:

“Actions undertaken to raise awareness and inform persons with disabilities and other parts of society about the Convention and the rights that it includes.”¹⁹

As part of the activities to raise awareness about the CRPD, two important points will need to be considered:

- **Translation:** an accurate translation of the text of the CRPD must be prepared and publicized widely if persons with disabilities are to be made aware of their rights.²⁰
- Accessibility:** Article 49 of the CRPD requires that the CRPD is made available in accessible formats.

Harmonizing National Law and Policy with the CRPD

Governments must ensure that their laws and practice are consistent with the CRPD. They must “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities” (see Article 4(1)(b)).

Thus, the Office of the High Commissioner for Human Rights advises that “one of the first steps that States need to undertake is a comprehensive review of national legislation and policy” and that this should “extend to areas that go beyond the traditional scope of disability legislation.”²¹ A government should undertake such reviews “as soon as possible after it has become party to the Convention, and preferably after it has signed the [CRPD]”²² The CRPD Committee also advises States that they will need to report on whether they have “adopted comprehensive disability discrimination legislation to put into effect provisions of the Convention.”²³

This Guide, among other things, is intended to assist governments in undertaking such a comprehensive review in the context of Article 19 of the CRPD.

National Monitoring

Article 33 requires States to establish a range of mechanisms for the implementation and monitoring of the CRPD. These include one or more focal points within government (for the coordination of the CRPD’s implementation) and an independent mechanism to promote, protect and monitor implementation of the CRPD.

¹⁹ CRPD/C/2/3 page 8

²⁰ In some countries disability organizations have highlighted concerns about the accuracy of the translation of the CRPD. See for example A/HRC/WG.6/9/HRV/3 noting such concerns raised by the Association for Self Advocacy, Croatia.

²¹ A/HRC/10/48, paras. 30 and 31

²² Handbook for Parliamentarians, 71

²³ CRPD/C/2/3 A.3.2 (b)

Participation

Full and effective participation and inclusion in society is one of the general, overarching principles of the CRPD set out in Article 3. This principle is reflected in Article 4(3) which requires governments to “consult closely” with, and actively involve, people with disabilities in the development and implementation of legislation and policies and in other decision-making processes that relate to them. Article 33(3) also highlights the importance of participation in relation to monitoring the implementation of the CRPD:

“Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

Civil society should also be involved in the international monitoring of States’ implementation of the CRPD. In its guidelines to States on preparing their periodic reports, the CRPD Committee emphasizes the importance of encouraging and facilitating “the involvement of non-governmental organizations, including organizations of persons with disabilities in the preparation of reports.” The reports will need to explain how this was achieved.²⁴

Checklist: General Issues for Implementation

The checklist on the following page suggests a series of questions for each of the five key areas for implementation of the CRPD discussed above. These questions can be added to and adapted depending on specific areas of interest and/or concern. They are intended to assist in the following objectives:

- Obtaining an overview of the initial work undertaken by the government after ratification
- Highlighting the importance of involving people with disabilities in the CRPD implementation process
- Establishing contact with national monitoring bodies (focal points and independent monitoring bodies)
- Gathering information to be used in independent reports, including shadow reports to the CRPD Committee.

²⁴ CRPD/C/2/3/ page 2

Checklist 1: General Issues for Implementation²⁵

1. Scope and status of the CRPD

1. Has the State made a reservation to the CRPD?
2. If yes, are the reasons made public?
3. Has the CRPD been incorporated into national (domestic) law? If not, are there plans to incorporate it?

2. Raising awareness about the CRPD

4. What action (if any) has the government taken to raise awareness about the CRPD within the general public, explaining its importance to people with disabilities?
5. Is an accurate official translation of the CRPD (and if ratified, the Optional Protocol) available?
6. Has the official translation of the text been widely disseminated?
7. Has the text been made available in accessible formats?

3. Harmonizing national law and policy with the CRPD

8. Has a review of national legislation and policies for compliance with the CRPD been initiated? What is the scope of this review, i.e. is it the comprehensive review required by the CRPD?
9. Have civil society and organizations of persons with disabilities been invited to make submissions on this review?
10. How does the government plan to coordinate the work to implement the CRPD across relevant government bodies?

4. National monitoring

11. What arrangements are in place to oversee the implementation of the CRPD as required by Article 33 of the CRPD?
12. Do such arrangements include:
 - One or more focal points within government? If so, is information about the focal point (e.g. the name(s) of the person/Ministry/organization undertaking this role and how to contact them) publicized?
 - One or more independent bodies whose specific functions are to promote and protect human rights?

5. Participation

13. What systems are in place to enable people with disabilities to be consulted about, and be actively involved in, the development and implementation of legislation, policies and other decision-making processes that affect them?
14. How are people with disabilities involved in monitoring the government's progress in implementing the CRPD (national and international)?

²⁵ See Annex 3 for additional sources of information on monitoring; some of the questions in the checklists in this guide have been adapted from these publications.

Chapter 4: Action to Implement Article 19

This chapter considers the steps that governments should take to meet their obligations under Article 19. It explains why States need to establish a clear action plan for the implementation of the reforms necessary to comply with Article 19. For countries in which the institutionalization of people with disabilities is still the predominant form of care, such implementation plans should include a national strategy for the transfer of institutional care to a system of community-based services and supports.

Required Action by States to Comply with Article 19

Some obligations under Article 19 must be addressed by governments immediately, while others can be met over time. This is because Article 19 combines elements of civil and political rights, such as the right to liberty,²⁶ with elements of economic, social, and cultural rights, such as the right to access to a range of community based support services.²⁷

The economic, social, and cultural aspects of Article 19 are subject to the concept of progressive realization, which takes into account that the arrangements needed to meet such rights may take time to put in place and be subject to resource constraints. However, this can never be an excuse for inaction. This is because the concept of progressive realization (see box) and the requirements under Article 19 make clear that governments must have in place concrete action plans for realizing the rights under Article 19.

Furthermore, the CRPD Committee expects States to monitor their progress in realizing the rights under the CRPD and report on such progress in their periodic reports. Specifically, the CRPD Committee states that the periodic reports should indicate where there are:

“Any mechanisms in place to monitor progress towards the full realization of the Convention rights, including recognition of indicators and related national benchmarks in relation to each Convention right.”²⁸

Compliance with Article 19 therefore requires concerted and continuing efforts by States, governed by a plan of action, to address the areas in which they do not meet the CRPD’s requirements. As highlighted in Chapter 3, the participation of civil society is crucial to the effective implementation and monitoring of the CRPD. Thus, States will need to work with people with disabilities and other individuals and organizations across a range of sectors in identifying and pursuing the necessary reforms. Such reforms must also be undertaken within an acceptable timescale.

²⁶ For example, Article 19 states that individuals should “not be obliged to live in a particular living arrangement” and therefore is linked to Article 14 (Liberty and security of person).

²⁷ Compare with Article 26 (Habilitation and rehabilitation).

²⁸ CRPD/C/2/3, A.3.2(c)

Progressive Realization of Economic, Social, and Cultural Rights

The concept of progressive realization recognizes that the implementation of some rights depends upon specific measures being undertaken and may be subject to resource constraints. This is relevant to some parts of Article 19. For example, it may take time for some States to meet the requirement under Article 19 that people with disabilities have access to the full range of community support services, particularly in those countries that have little or no community-based services and limited resources.

However, the lack of resources does not mean that governments can justify doing nothing, as Article 4(2) of the CRPD makes clear in referring to States taking measures with a view “to achieving progressively the full realisation of these rights” (hence the term progressive realization).

The doctrine of progressive realization also requires that States expend the “maximum available resources” on the fulfillment of economic, social, and cultural rights and that they do not “retrogress” in the fulfillment of these rights. It also makes clear that some obligations take immediate effect, such as the duty to ensure that rights can be exercised without discrimination and that minimum core obligations are met (for example States will be failing to discharge their duties “if any significant number of individuals is deprived of essential food stuffs, or essential primary health care, of basic shelter and housing, or the most basic forms of education”²⁹).

Required Steps to Initiate the Implementation of Article 19

The action to be taken by States as part of their “effective and appropriate measures” to implement the Convention will vary depending on the country context. However, in all cases, as three broad initial steps in the implementation of Article 19, governments will be expected to:

- *Provide explicit recognition of the right of people with disabilities to live independently and be included in the community (‘the right to community living’):* See Article 19, “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others.”
- *Establish mechanisms for participation:* This is necessary to ensure the full inclusion and participation of people with disabilities. It is also essential to enable people with disabilities to participate in the development and implementation of legislation and policies to implement Article 19, as required under Article 4(3).
- *Initiate an action plan:* Such plans will be necessary to show how and when governments intend to take the required action (i.e. to demonstrate that they are taking effective and appropriate measures to ensure that people with disabilities have the full enjoyment of the right to community living, with choices equal to others, as required by Article 19).

²⁹ See General Comment 3 (The nature of States parties obligations) of the Committee of the International Covenant of Economic, Social and Cultural Rights)

Implementing Article 19: Community for All Checklist

In order to implement Article 19, governments must:

- Identify the aspects of Article 19 with which they do not yet comply; and
- Demonstrate that they are pursuing concrete, time-bound and targeted action to address areas of non-compliance, within an acceptable timescale.

Although the specific activities required in order to implement Article 19 will differ among countries, depending on their particular circumstances, there is a range of issues that are likely to be common to many. Based upon the provisions of Article 19 and other articles of the CRPD (such as Article 4), the *Community for All* Checklist below suggests 10 areas that will need to be addressed when planning how to implement Article 19. It focuses on the action to be taken by governments of countries in which people with disabilities continue to be institutionalized.

Community for All Checklist

1. Commit to transforming the system from institutional services to community-based services
2. Provide explicit recognition of the right to community living for all (the right of all persons with disabilities to live in the community, with choices equal to others)
3. Develop a national strategy for transforming the system from institutional placements to community-based services and supports
4. Establish mechanisms to enable the participation of civil society, in particular, people with disabilities and their families
5. Develop links with experts (international and national)
6. Review legislation, policies, and practices relevant to the implementation of Article 19
7. Review existing services for people with disabilities
8. Ensure transparency and accountability in the use of public funds
9. Establish mechanisms for data collection
10. Establish mechanisms for periodic review of the action plan and national strategy

Further information on each of these ten action points is provided in the next section, including an explanation of how these points relate to the rights and obligations under the CRPD. This is followed by a list of questions for each of the ten headings of the checklist for *A Community for All*.

A Community for All: Checklist

1. Commit to transforming the system from institutional services to community-based services

As stated in Chapter 2, while Article 19 makes no specific reference to closing long-stay institutions, its provisions make clear that their closure will be required. This is because the obligations under Article 19 cannot be met if people continue to be placed in institutions.

- The emphasis of the CRPD is on full inclusion and participation in the community
- States must take action to ensure that people with disabilities have access to community services that “support living and inclusion in the community” and “prevent isolation or segregation from the community.”

While the shift from institutional services to community-based services and the implementation of policies that promote inclusion cannot be implemented overnight, governments can make firm commitments including concrete plans to achieve this change. An explicit commitment is a necessary first step to meeting this intrinsic obligation of Article 19.

2. Provide explicit recognition of the right to community living for all (the right of all persons with disabilities to live in the community, with choices equal to others)

Formal recognition of this right, principally by including it in national legislation, will be necessary to ensure that it is respected by policymakers and others involved in developing and implementing policy and legislation affecting people with disabilities.

- The Office of the High Commissioner for Human Rights comments that for the effective implementation of national strategies the independent living principle should be “rooted in a legislative framework” and clearly established as a legal right, placing duties on authorities and service providers, and allowing for recourse in case of violation.
- Furthermore: “Such legislative frameworks shall include the recognition of the right to access the support services required to enable independent living and inclusion in community life, and the guarantee that independent living support should be provided and arranged on the basis of the individual’s own choices and aspirations, in line with the principles of the Convention.”³⁰

3. Develop a national strategy for the transformation of institutional placements to community-based services and supports

In order to translate their commitment to establishing alternatives into concrete action, States must establish clear, measurable and time-bound action plans with specific targets for achieving success.³¹ Given the complexities inherent in such systemic change, such plans

³⁰ A/HRC/10/48, para. 50

³¹ See also, Data Collection.

will be essential. These plans should address specific actions that will be necessary to meet the requirements of Article 19.

The Office of the High Commissioner for Human Rights comments that in most cases “a national strategy that integrates interventions in the area of social services, health, housing and employment, at a very minimum will be required.”³² Similarly, in its discussion on how governments can develop successful strategies for replacing institutions with community-based services, the DECLOC report recommended that: “Ideally, the transition from institutions to services in the community will have a national mandate. At the very least, there need to be local agreements between all potential service providers. This plan should not just specify that an institution will close and indicate the target date, but should include a detailed vision of the future care system. Consultation should be wide, and users and families should be involved throughout.”³³

The box below suggests some essential points to include in national strategies. In order to comply with their obligations on participation (see bullet point 4) governments must consult with people with disabilities in the development of such strategies.

From Institutional Care to Community-based Services: Points to Include in a National Strategy

- Statement that long-stay institutions are to close
- Target date for the closure of the institution(s)
- Measurable timetables including progress that can be quantified
- Prohibiting admissions to long-stay institutions
- Description of the range of community based services that are to be developed (with an emphasis on ensuring that people with disabilities can participate in community life)
- Recognition of the need to develop clear standards for all community-based services and that such standards will be developed in close collaboration with people with disabilities and their families
- Financing and capacity building for NGOs and other community-based service providers
- Target to move a certain number of people (or a certain % of the residents) from long-stay institutions each year
- Recognition that the development of community-based services must be based on actual needs that will differ between localities.
- Redirection of financing from institutions to the community-based services
- Mechanisms for review, for example identifying, and taking action to address, cases of re-institutionalization and taking into account the outcomes of reviews into relevant legislation, policy and practice.

³² A/HRC/10/48, para. 50

³³ Pages 96- 97

4. Establish mechanisms to enable the participation of civil society, in particular people with disabilities and their families

All the work identified as necessary for the implementation of Article 19 should involve people with disabilities. As discussed in Chapter 3, the CRPD highlights the importance of the participation of civil society, especially of people with disabilities in the development and implementation of legislation and policies and in other decision-making processes that relate to them.

Article 26, which concerns the provision of comprehensive habilitation and rehabilitation services particularly in the areas of health, employment, education, and social services, also emphasizes the importance of participation in this area, requiring States to develop such services so that they support participation and inclusion in society.

States will therefore need to create systems for involving people with disabilities and their families in all aspects of the process (developing, reviewing the implementation of, and revising the strategy); the development of policy and legislation relevant to the realization of Article 19 and in the planning, monitoring, and evaluation of services for people with disabilities. Thus, mechanisms for participation will be needed in three areas:

- General measures for participation as required under the CRPD
- Involvement in the process of implementing Article 19
- Feedback on the quality of services

5. Develop links with experts (international and national)

States should seek to establish links with individuals and organizations (national and international) that can offer relevant expertise, for example in the closure of institutions and the development of community-based services, and in ensuring the active involvement of people with disabilities in the development of policy and practice.

- Article 32 highlights the importance of international cooperation between States, relevant international and regional organizations, and civil society to support national efforts to realize the rights under the CRPD.
- The CRPD Committee advises that States should indicate what actions they have taken towards: “facilitating and supporting capacity-building, including through exchange and sharing of information, experiences, training programs, and best practice.”³⁴

6. Review legislation and policies relevant to the implementation of Article 19

Laws and policies can either interfere with, or enable, the enjoyment of Article 19, and States should review their legal and policy frameworks with a view to establishing an enabling legal and policy environment for the enjoyment of this right. This review should be part of the comprehensive review discussed in Chapter 3 (“Harmonizing national law and policy with the CRPD”). States must also take action to prohibit discrimination of any kind on the grounds of disability. The Handbook for Parliamentarians advises:

³⁴ CRPD/C/2/3, 19

*A State should carefully review its laws and their operation, particularly in areas such as deprivation of persons with disabilities, including those with intellectual and mental disabilities. For example, States should note the Convention's requirements on independent living within the community instead of forced institutionalization or forced medical interventions, and should ensure that there are laws and procedures to monitor the operation of this legislation, investigate cases of abuse and impose punitive measures, as necessary (article 16(4)).*³⁵

The legal and policy review in relation to Article 19 will need to be wide-ranging since Article 19 is dependent on the enjoyment of a range of other rights, such as the right to education, the right to work and employment, the right to habilitation and rehabilitation and the right to health. Laws and policies related to the following areas will be of key relevance:

- Access to the support services necessary to enable people with disabilities to live and participate in the community (including supporting families of people with disabilities – see Article 23(3))
- Involuntary admission to institutions
- Consent to treatment and the right to refuse it
- Decision-making (e.g. guardianship laws)
- Social exclusion (including anti-discrimination legislation covering areas such as employment, education, and the provision of goods and services)
- Monitoring of institutions and handling of complaints

The review of legislation and policy is another area in which the CRPD requires the participation of civil society organizations and in particular organizations of people with disabilities.³⁶

7. Review existing services for people with disabilities

The review of services for people with disabilities covers two main areas explicitly recognized in the CRPD:

- *Access to a range of community support services:* The development of community-based services as alternatives to institutional care is crucial to States' compliance with Article 19. Without such services people with disabilities have no real choice about where they live. The CRPD requires that people 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" (Article 19(b)). Thus, it will be important to ascertain what support services are available to people with disabilities, and what services will need to be developed to enable them to exercise their freedom to live in and be part of the community.

³⁵ United Nations, From exclusion to equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, Geneva 2007, p. 70

³⁶ UN A/HRC/10/48 para 31

The suggested questions in relation to “Access to a range of community support services” in the following checklist reflect the approach taken by the Committee responsible for monitoring the International Covenant on Economic, Social and Cultural Rights (ICESCR) in their General Comment on the right to the highest attainable standard of health.³⁷ In assessing States’ progress in meeting this aspect of Article 19, consideration can be given to whether services are available, accessible, acceptable, and of good quality.

- *Equal access to mainstream community services:* The CRPD requires that “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(c)). It will be important to ascertain whether people with disabilities have the same access to mainstream community services and facilities as non-disabled citizens, taking into account the principle of reasonable accommodation.³⁸

8. Ensure transparency and accountability in the use of public funds

Like laws and policies, public funds can be directed either to support or interfere with the enjoyment of Article 19. Thus this will be an important aspect of the work to monitor and ensure the implementation of the CRPD.

- The United Nations’ guide on monitoring the CRPD highlights the importance of budget monitoring, pointing out that ‘some of the obligations on States require the allocation of financial and human resources to ensure that positive steps are taken to promote the rights of persons with disabilities and that they are effective. Accordingly:

Budget analysis might be relevant to issues such as accessibility, support for persons with disabilities, including supported decision-making, inclusive education, medical services, social protection and national monitoring mechanisms. Monitors engaging in budget analysis might examine financial commitments in national disability plans of action, budgets from the ministries of education, public works or social affairs, and the budget of national human rights institutions.³⁹

- The United Nations also points out: “States are forbidden from taking regressive steps or measures that diminish the enjoyment of economic, social and cultural rights.”⁴⁰ An example of such a regressive step would be for a State to invest resources in building new long-stay institutions or renovating existing ones rather than developing community-based alternatives to institutional care. Each State should therefore include a prohibition

³⁷ See also A/HRC/7/11 - Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Paul Hunt) to the Human Rights Council, in response to its request that he “identify and explore the key features of an effective, integrated and accessible health system from the perspective of the right to health, bearing in mind the level of development of countries.”

³⁸ This is defined in Article 2 CRPD

³⁹ United Nations, Monitoring the Convention on the Rights of Persons with Disabilities, 2010, page 42

⁴⁰ As above, page 30

on building new institutions or renovating existing institutions,⁴¹ and a commitment to allocating the “maximum of its available resources” to developing community-based services.

9. Establish mechanisms for data collection

Governments will need to collect relevant data on the development and implementation of policies that give effect to Article 19. Data collection is a key element of accountability that enables States to determine whether they are meeting their targets related to deinstitutionalization and the right to community living.

- Article 31 requires States to collect “appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the [CRPD].”
- The DECLOC report noted that such information is needed to review progress against targets on the closure of institutions and of the growth of independent living and other services in the community. The report recommended: “The data set needs to include sufficient information about the people served (gender, ethnicity, primary disability) to enable States to ensure that everyone is benefiting from the transition away from institutions to better alternatives in the community.”⁴²
- The CRPD Committee asks that States indicate in their periodic reports: “Statistical data on the realization of each Convention right, disaggregated by sex, age, type of disability (physical, sensory, intellectual and mental), ethnic origin, urban/rural population and other relevant categories, on an annual comparative basis over the past four years.”⁴³

10. Establish mechanisms for review of the Article 19 Implementation Plan and national strategy

As discussed in Chapter 3, the CRPD Committee will expect to receive information on how States are monitoring their progress in implementing the CRPD. Establishing a robust system for monitoring progress in the implementation of Article 19 will be crucial if governments are to demonstrate that they are taking concrete action to realize the right to community living. Reviewing progress towards realizing this right will also be essential for policymakers and others involved in achieving the transition from a system of institutionalization to community-based services and support for people with disabilities. This will be necessary to enable any problems to be identified and addressed as well as ensuring that the planned activities are being completed within the agreed timetable.

⁴¹ While there may be cases in which funding is required to renovate existing institutions in order to address urgent and life threatening risks to residents’ health or safety, such work must only happen to ensure life saving measures and must not detract from the development of alternative community based services.

⁴² Page 94

⁴³ CRPD/C/2/3, page 4

- The Office of the High Commissioner for Human Rights (OHCHR) suggests that in relation to economic and social rights (of which Article 19 is one) States can develop a plan of action which would cover:
 - a clear timeframe for implementing the right(s),
 - time-bound benchmarks of achievement, and
 - indicators of success.⁴⁴

- Where a government has published an action plan for the implementation of Article 19, such as the OHCHR describes, or a national strategy, it should be possible to ascertain whether the work specified in such plans or strategies are being undertaken within the agreed timescale. Where deadlines are not met, the reasons need to be considered and a revised timetable agreed.

A Community for All Checklist: Questions

Set out below are a series of suggested questions for each of the ten action points in the *Community for All Checklist*. These questions can be added to and adapted as required depending on the specific areas of interest and/or concern. They are intended to help those seeking to promote community living to:

- Highlight the range of activities that need to be undertaken by governments if they are to comply with their obligations under Article 19
- Emphasize that immediate action is required: lack of resources is not an excuse for inaction
- Assess what action is needed with comply with Article 19 and whether governments have put in place concrete plans to take such action.
- Gather information on areas of particular interest. For example, some of the questions such as those relating to point 5, “Review existing services for people with disabilities,” could be used as part of a baseline survey to assess the situation of people with disabilities in institutions and the current availability of community-based services. This initial survey could be repeated at a subsequent date (for example, one year later) to assess what progress has been made in the intervening period.

⁴⁴ Monitoring the Convention on the Rights of Persons with Disabilities, page 29

Checklist 2: Recommended Action for Implementing Article 19

1. Commit to transforming the system from institutional services to community-based services

- Beyond ratifying the CRPD itself, has the Government made an explicit commitment to transforming the system from institutional services to community-based services?
- If so, how? For example is this commitment set out in the national strategy? (See number 3)

2. Provide explicit recognition of the right to community living for all (the right of all persons with disabilities to live in the community, with choices equal to others)

- Does the constitution and/or legislation “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others”?
- If so, does this right include all people with disabilities? (For example, do the terms: *disability*, *people with disabilities*, and *persons with disabilities* include people with intellectual disabilities and mental health problems?)
- Is the promotion of the social inclusion of people with disabilities made explicit in legislation and/or policies?
- Are individuals recognized as having the right to decide for themselves where they would like to live and provided with the necessary support to make such decisions?

3. Develop a national strategy for the transformation from institutional placements to community-based services

- Is there a national strategy for the transformation from institutional care to community-based care?
- Does the strategy describe the range of community-based services to be provided, e.g. housing (including supported housing), care in the family home, social work support, early intervention services, or vocational training?
- Does the strategy include the following:
 - a clear timetable for action (e.g. development of community-based services) and targets and benchmarks for measuring progress (e.g. a target date for the closure of institutions and details of how many residents will leave the institution during a given period), and
 - budget and resources allocation (between institutions and community-based services)?
- Is the strategy supported by all relevant government bodies, e.g. Ministry of Health, Ministry of Social Welfare, Ministry of Education, Ministry of Finance, etc.? If so, how will they be involved, i.e. does the strategy explain each department’s responsibilities and/or their contribution of resources as well as how they will coordinate among themselves?

- Are there separate action plans for the closure of each institution and the redirection of its budget once the appropriate community-based services have been developed?
- Will the strategy take the review of legislation and policies into account?

4. Establish mechanisms to enable the participation of civil society, in particular people with disabilities and their families

General measures required under the CRPD (Taken from Checklist 1):

- Are there clear mechanisms for consulting people with disabilities and their families in the development and implementation of legislation and policies and other decision-making processes that affect them?
- How are people with disabilities involved in monitoring the government's progress in implementing the CRPD (national and international)?

Involvement in the process of implementing Article 19:

- What systems have been established to ensure that people with disabilities, family members, and other advocates for community living are involved in developing, implementing, and reviewing the activities to implement Article 19? Are these systems working effectively?
- Does the government provide support (including financial support) to groups of people with disabilities and others advocating for the development of community based services as alternatives to institutions?
- Do people with disabilities and families have access to training on how policy-making works and how they can influence it?
- Do policymakers and government officials meet regularly with organizations of people with disabilities and families to discuss aspects of policy and practice concerning the development of alternatives to institutional care and related matters (such as monitoring the situation in existing institutions)?
- If meetings are held, are they accessible, e.g. the venues have disabled access and the information is provided in appropriate formats such as easy-to-read documents for people with intellectual disabilities?

Views on the quality of services

- Are people with disabilities and, when appropriate, their families included in monitoring and evaluation systems, such as inspectorates that visit and review services for people with disabilities?

5. Develop links with experts (international and national)

- If there are existing community-based services, have efforts been made to find out who developed them and how they are financed?

- If there are no community-based services, have efforts been made to arrange visits to services in neighboring countries with a view toward adapting those models to the country context and learning how deinstitutionalization was achieved?

6. Review legislation, policies, and practices relevant to the implementation of Article 19

General Issues

- Has a review of national legislation and policies for compliance with the CRPD been initiated? (See questions under point 3, “Harmonizing national law and policy with the CRPD,” Checklist 1) Does it include specific issues relevant to Article 19?
- Is there a time table for:
 - Submitting comments to this review?
 - Publication of the findings?

Specific issues

- Does the review address key areas of concern, e.g. the use (and abuse) of guardianship and any existing legislative/policy barriers to the development of community-based services, including the prohibition of NGOs providing such services?
- Are there laws that restrict or remove individuals’ legal capacity to make decision about where and with whom they live? Do guardianship laws allow guardians to require their wards to live in a particular place? Note that such laws will need to be reviewed in accordance with Article 12 (Equal recognition before the law). The CRPD Committee is developing a General Comment on Article 12.
- Are there any other circumstances in which people with disabilities are obliged to live in a particular living arrangement? (See Article 19(a))
- Does legislation permit detention in some circumstances, e.g. mental health legislation? If so, does this accord with human rights standards, including Article 14 (Right to liberty and security of person)? For example:
 - Do people with disabilities enjoy the right to liberty, on an equal basis as others, e.g., they are not deprived of their liberty unlawfully or arbitrarily and any deprivation is in accordance with the law and “the existence of a disability shall in no case justify a deprivation of liberty”?
 - If the placement of a person with disabilities amounts to a deprivation of liberty, is that person entitled to the same guarantees under international human rights law as others? (For example is a periodic review of their detention carried out in accordance with Article 5(4) of the European Convention on Human Rights?)
- Are there any laws and policies that highlight the importance of providing support to disabled people to enable them to make decisions (such as where and with whom to live) for themselves? (See Article 12(3))
- Are there laws and policies that mandate and set out a process for the creation and oversight of a range of community-based services as required by the CRPD?

- Are there laws and policies that mandate and define equal access to mainstream community services and provide redress for discrimination including lack of reasonable accommodation?

7. Review existing services for people with disabilities

The following questions about access to community support services and access to mainstream community services will assist in assessing whether people with disabilities are able to choose their place of residence on an equal basis with others.

Access to a range of community support services

i. Availability of community-based services

- What community support services are available? (Services might include home support, early intervention, education, supported employment, community living, respite care, rehabilitation, medication and psychotherapy.)
- Is suitable accommodation available as an alternative to institutional care? For example, can people who are now living in institutions move to the community? If not, why not?
- Are community-based services available to all those in need of such services?
- Is there a sufficient number of appropriately trained staff, including direct caregivers (for example, social workers, clinical psychologists, psychiatrists, occupational therapists, and speech therapists)?
- What are the barriers to the availability of services? For example:
 - Are there legal or other restrictions to nongovernmental organizations providing community based services?
 - Is existing funding adequate to facilitate the development of quality community-based services?
 - Is the funding for community-based services equal to funding for institutions (per person)?

ii. Accessibility of community-based services

There are 4 dimensions to this issue: non-discrimination; physical accessibility; economic accessibility, and information accessibility:

Non-discrimination

- Are the services accessible to all people with disabilities without discrimination on the basis of disability, gender, age, or ethnic origin?

Physical accessibility

- Are services provided in communities where people receiving such services live or work?
- Are the buildings in which the services are provided accessible for wheelchair users and others with mobility restrictions?

Economic accessibility – affordable services

- Are the services made free of charge to people with disabilities, or if not, can people with disabilities afford to pay for these services?

Information

- Are people with disabilities given the information that they need to make decisions about the services they receive? For example, are they informed about the alternatives to institutional care?
 - In what situations, if any, are people with mental health problems and/or intellectual disabilities not provided with information because they are presumed to lack capacity to make decisions for themselves?
 - Is the information given to people with disabilities about the services that they receive provided in a format that is accessible to them? For example, for people with intellectual disabilities, in an easy-to-read format?

iii. Acceptability of the services

- Do the services recognize and respect the diverse individual needs, values and circumstances of the people receiving them, including race, religion, culture, gender, age, sexual orientation as well as disability?
- Are care plans developed for each individual, based on discussions with that person and other relevant people, and are these plans reviewed on at least an annual basis?
- Are the services provided in a way that is respectful of people's rights, e.g. to consent, confidentiality, and privacy?

iv. Quality of the services

- Have staff received appropriate training (initial training and regular refresher courses)?
- Do professionals and staff working with people with disabilities receive training on the rights set out in the CRPD so they can provide the assistance and services guaranteed by the CRPD? (Article 4(i))
- What mechanisms are in place for the monitoring and evaluation of services?

v. Promotion of social inclusion

- Do the services assist people with disabilities to participate in the community and prevent their isolation or segregation from the community?
- Are the services designed to promote and encourage people with disabilities' autonomy and their social inclusion?
- How do services enable people with disabilities to engage in community activities?
- Are people with disabilities welcomed and supported to participate in the community? If not, what action is taken to address this?

- What are the barriers, if any, to the participation of people with disabilities in the community?

Equal access to mainstream community services

- Are all mainstream services available to people with disabilities (for example public transport, health services, housing, and leisure)?
- In what situations, if any, are people with disabilities denied services on the grounds of their disability?
- What are the barriers, if any, to people with disabilities being able to use mainstream services? If there are barriers, what steps are being taken to overcome them? States will be required to make “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case,” to ensure that people with disabilities can exercise their rights on an equal basis with others (this is known as “reasonable accommodation” – see Article 2 of the CRPD).

8. Ensure transparency and accountability in the use of public funds

- Is the use of public funds and/or donor funding to build new institutions or renovate existing institutions prohibited?
- Is there a commitment to allocating the “maximum of its available resources” to developing community-based services?
- What information is available on the operating cost of institutions and which Ministry (or Ministries) is responsible for the funding of institutions? Is international donor funding used for institutions?
- What happens to the institutions’ funding when residents move into the community?
- Can governments contract with NGOs to deliver services in the community?
- What funding is allocated to the planning, development, and provision of community-based services and family support? What is the source of this funding, e.g. is it mostly donor funding?

9. Establish mechanisms for data collection

- What are the government’s targets and benchmarks for realizing the right to community living?
- What information is collected by the government to assist it in formulating and implementing its policies in relation to people with disabilities?
- Does the information include the number of people with disabilities who are placed in

residential institutions?

- Is the information disaggregated by (a) primary disability, (b) gender, (c) ethnicity, and (d) age?

10. Establish mechanisms for review for the Article 19 implementation plan and national strategy

- How is progress being monitored (i.e. have specific targets and timescales been identified)?
- How often is the action plan reviewed to identify barriers to implementation and make necessary modifications to the plan and timetable for action?
- What areas are covered by the review? For example:
 - Where progress is slower than expected or has halted, what is the reason for this? How can the problem(s) be addressed?
 - Does the review consider what barriers there might be to people with disabilities choosing where they wish to live? (There may be a range of reasons why people with disabilities are prevented from exercising choice, for example, there are no organizations that provide supported housing services to people with disabilities.)

Annex 1: Monitoring the Implementation of the CRPD

This Annex provides a summary of the mechanisms, both international and national, that States are required to put in place for monitoring the implementation of the CRPD.

1. International Monitoring

International monitoring is undertaken by the CRPD Committee and the Conference of States Parties.

The Committee on the Rights of Persons with Disabilities (CRPD Committee)

The CRPD Committee is made up of 18 members, all of whom serve in their personal capacity and are considered to be experts in disability and other fields relevant to the CRPD. The members were appointed following the CRPD's entry into force (after 20 States had ratified the CRPD). Information on the CRPD is available at:

www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

The CRPD Committee has a range of monitoring responsibilities:

- a. **Reviewing States periodic reports:** Article 35(1) requires each State that has ratified the CRPD to submit a comprehensive report outlining the steps it has taken to meet its obligations under the CRPD and the progress it has made in meeting these obligations.
 - The first report must be submitted within two years of the State being bound by the CRPD.
 - Subsequent reports must be submitted at least every four years, and whenever the Committee requests them.
 - The CRPD Committee has issued guidelines to advise States on the form and content of their reports (see *Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities* (CRPD/C/2/3, 18 November 2009).
 - The CRPD Committee guidelines emphasize the importance of encouraging and facilitating “the involvement of nongovernmental organizations, including organizations of persons with disabilities in the preparation of reports.” States’ reports will need to explain how this was achieved.
 - In relation to Article 19, the CRPD Committee expects States to report on the following areas:
 - The existence of available independent living schemes, including the provision of personal assistants for persons who so require
 - The existence of in-house support services allowing persons with disabilities to live in their community
 - The existence and range of options of residential services for living arrangements, including shared and sheltered accommodation which take into account the form of disability

- The degree of accessibility for persons with disabilities to community services and facilities provided to the general population.⁴⁵
- b. **Examining individual complaints:** if the State has ratified the Optional Protocol to the CRPD, the Committee may receive and consider complaints (referred to as a “communication”) from, or on behalf of, individuals who claim to be victims of the State’s failure to comply with its obligations under the CRPD.⁴⁶
- c. **Conducting inquiries:** if the State has agreed to this procedure when ratifying the Optional Protocol to the CRPD, the Committee can undertake inquiries where it has received “reliable information indicating grave or systematic violations by a State Party.”⁴⁷
- d. **Reporting to the UN:** every two years the CRPD Committee is required to report to the General Assembly and the Economic and Social Council on its activities and may make suggestions and general recommendations based on the examination of reports and information received from State Parties.⁴⁸
- e. **Additional activities:** the CRPD Committee may also:
 - Issue general comments elaborating the meaning of the provisions of the Convention or about cross-cutting themes.
 - Hold days of general discussion with States, civil society, United Nations entities and other international organizations.

The Conference of States Parties

Article 40 of the CRPD provides that “States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.” The first session was held in November 2008 and the most recent session was held 7 – 9 September 2011. Further information can be obtained from the Enable website: www.un.org/disabilities/.

2. National Monitoring

Article 33 of the CRPD requires States to establish a range of mechanisms to oversee the implementation of the CRPD. This is the first human rights treaty that contains detailed provisions on national monitoring and implementation frameworks.⁴⁹ The mechanisms envisaged are described below:

- a. **Focal points within government:** States are required to designate one or more “focal points” within government for matters relating to the implementation of the CRPD (33(1)).

⁴⁵ See page 12 of the CRPD Guidelines (CRPD/C/2/2)

⁴⁶ See Article 1 of the Optional Protocol

⁴⁷ See Article 6 of the Optional Protocol

⁴⁸ See Article 39 of the CRPD

⁴⁹ See Chapter 7 of *Handbook for Parliamentarians - From Exclusion to Equality – Realizing the Rights of Persons with Disabilities*, United Nations, 2007 for further information.

- The Office of the High Commissioner for Human Rights suggests that focal points should be appointed for each (or most) governmental department/Ministry in addition to designating “one overall focal point within government responsible for the implementation of the Convention.”⁵⁰
 - The focal point should play a leading role in coordinating the implementation of the CRPD.
- b. **Coordination mechanism:** States are also asked to consider establishing a means of coordinating the work to implement the CRPD across government “to facilitate related action in different sectors and at different levels” 33(1).
- Given that the implementation of the CRPD will require the involvement of a wide range of government departments, establishing such a coordination mechanism is advisable.
 - The Handbook for Parliamentarians suggests⁵¹ that coordination mechanisms should ideally:
 - Consist of a permanent structure with arrangements to allow coordination across government
 - Ensure coordination at local, regional, and national/federal levels
 - Ensure the participation of persons with disabilities, organizations of disabled persons and NGOs by establishing a permanent forum for discussion with civil society.
- c. **Independent Mechanism(s) to promote, protect, and monitor the CRPD’s implementation:** States are required to establish “one or more independent mechanisms as appropriate, to promote, protect, and monitor implementation” of the CRPD (33(2)).
- Although there is no specific requirement for governments to establish a national human rights institution (NHRI), when establishing this monitoring framework, States are required to “take into account the principles relating to the status and functioning of national human rights institutions for the protection and promotion of human rights.”
 - These principles, known as the Paris Principles, set standards for NHRIs. They address issues such as independence from government, have the power to make recommendations and proposals concerning existing and proposed laws and policies and have adequate powers of investigation, with the capacity to hear complaints and transmit them to the competent authorities.
 - The Handbook for Parliamentarians notes that in the light of this link, a NHRI “is the most likely form that an independent ‘framework’ would take in compliance with the national monitoring provisions under the Convention.”⁵²
- d. **Participation:** Article 33(3) makes specific provision for participation in monitoring the implementation of the CRPD: “Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

⁵⁰ Thematic study by the Office of the United Nations High Commissioner for Human Rights on the structure and role of national mechanisms for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities, A/HRC/13/29, 24

⁵¹ Pages 94 - 95

⁵² The Handbook for Parliamentarians provides detailed consideration of the scope and purpose of the independent monitoring mechanism. See pages 96 – 105. See also the Thematic Study, paragraphs 37 – 68.

- This requirement is in addition to Article 4(3) which requires States Parties to consult with and actively involve people with disabilities in the development and implementation of legislation and policies and in other decision-making processes that relate to them.

Annex 2: Promoting the Ratification of the CRPD

Once a government has signed the CRPD it should prepare to ratify it. The Office of the United Nations High Commissioner for Human Rights (OHCHR) considers that the process of ratification in countries “offer important opportunities for awareness raising and promoting understanding” of the CRPD.⁵³

Consequences of signing the CRPD and the obligation to promote community living

Although States that have signed but not ratified the CRPD are not bound by its obligations, they are required to “refrain from acts that would defeat the object and purpose of the treaty.”⁵⁴ This point is relevant where there are concerns that a government is extending the practice of institutionalization (for example, by building new long stay institutions) rather than developing community-based alternatives. A recent report published by the European Coalition for Community Living (ECCL) argues that States should take action to promote community living whether or not they have ratified the CRPD. This is because the right to community living is recognized by UN treaty bodies and European human rights treaties such as the EU Charter of Fundamental Rights and the Revised Social Charter (1996).⁵⁵

Action to Promote Ratification

The OHCHR suggests a range of steps that States could take between signature and ratification of the CRPD, including:

- Establish a review of national legislation and policies for compliance with the CRPD
- Undertake national consultations which include civil society and organizations of persons with disabilities
- Officially translating and widely disseminating the CRPD in national languages
- Publically launch the process of ratification
- Make publically available a plan that includes timelines and opportunities for consultation
- Invite civil society and organizations of persons with disabilities to make submissions, presenting their views on the opportunities and challenges of ratification
- Carefully consider the need to support the participation of organizations of people with disabilities in consultations, including with financial support.

Based upon the OHCHR’s recommended steps to prepare for ratification, the checklist below suggests questions to assist those wishing to promote the ratification of the CRPD and assess their government’s progress towards ratification.

⁵³ A/HRC/10/48, para15

⁵⁴ Vienna Convention on the Law of Treaties, Article 18

⁵⁵ Wasted time, wasted money, wasted lives...a wasted opportunity? A focus report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in CEE by failing to support the transition from institutional care to community-based alternatives, March 2010

Checklist: Action to Promote Ratification

Raising awareness about the CRPD

1. Is there an official translation of the CRPD into the national language(s)?
2. If yes, is this being disseminated widely?
3. Has there been a public launch for the ratification process?
4. If not, is a public launch planned?

A clear timetable for ratification

5. Has the government stated when it intends to ratify the CRPD?
6. Has the government stated what work needs to be done to prepare for ratification?
7. Has the government prepared a plan for undertaking such work?
8. If yes, does the plan give timelines for the completion of such work?
9. Does the plan state which stakeholders government intends to consult and how this consultation will take place?

Participation

10. Has there been any public consultation, which includes civil society and organizations of persons with disabilities, on the question of ratification?
11. Have civil society and organizations of people with disabilities been asked to comment on what they consider to be opportunities and challenges in ratification?
12. Has the government sought advice on how to support the participation of organizations of people with disabilities in consultations (for example, the provision of financial support)?

Review of legislation and policies

13. Has a review of national legislation and policies for compliance with the CRPD been established (i.e. to identify areas that are incompatible and need to be reformed)?
14. Have civil society and organizations of persons with disabilities been invited to comment on legislation review?

Annex 3: Resources

Community Living

Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent; p. 97 (further referred to as ‘the DECLOC report’)

Jan Pfeiffer et al, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, 2009

European Coalition for Community Living (C. Parker with I. Bulić), *Wasted time, wasted money, wasted lives – a wasted opportunity? A focus report on how the current use of Structural Funds perpetuates the social exclusion of disabled people by failing to support the transition from institutional care to community-based services*, European Coalition for Community Living March 2010, available at: www.community-living.info/

United Nations

The United Nations *Handbook for Parliamentarians - From exclusion to equality: Realizing the rights of persons with disabilities*, 2007. The handbook was jointly prepared by the Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Inter-Parliamentary Union (IPU).

Thematic study by 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, January 2009, A/HRC/10/48

Committee on the Rights of Persons with Disabilities *Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities* (CRPD/C/2/3, 2009)

United Nations, *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors*, 2010

Monitoring the CRPD

Phillip French, Disability Studies and Research Institute Human Rights Indicators for People with Disability, *A resource for disability activists and policy makers incorporating an introduction and commentary to the United Nations Convention on the Rights of Persons with Disabilities*, Queensland Advocacy Incorporated, October 2007

International Disability Alliance, Guidance Document, *Effective use of international human rights monitoring mechanisms to protect the rights of persons with disabilities*, May 2010