

*A Community for All Checklist*

Implementing Article 19 of the  
Convention on the Rights of  
Persons with Disabilities

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## Introduction

The Convention on the Rights of Persons with Disabilities (CRPD) is a powerful tool that can be used to promote the right of people with disabilities to live and participate in the community as equal citizens—to promote “a community for all.”

This *Community for All* Checklist, prepared by the Open Society Public Health Program, sets out 10 key areas of work that governments will need to take if they are to comply with their obligations under Article 19 of the CRPD, which provides unequivocally that people with disabilities have the right to live independently and be included in the community. The checklist includes an overview of the CRPD and its relevance to efforts to replace a system that institutionalizes people with disabilities 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.<sup>1</sup>

The *Community for All* Checklist forms the basis of a more detailed guide on the obligations of States under Article 19, with suggestions on how organizations of people with disabilities, human rights organizations, policy makers, and others advocating for reform in this area can monitor their governments progress in implementing Article 19. This guide is also available at: <http://www.soros.org/health/crpd>.

## The CRPD and Community Living

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 provides that people with disabilities have the right to live in the community, with the same choices as others. It requires States to take appropriate measures to facilitate “full inclusion and participation in the community” of persons with disabilities.

Accordingly, governments must not only take action to ensure that people with disabilities can live in the community, they must also provide the support and structures that enable them to engage in community life. This right applies to all persons with disabilities, regardless of the degree of the disability or the level of support necessary. 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, supported employment, as well as access to mainstream services such as health care.

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<sup>1</sup> The areas of work suggested in this checklist are based on relevant CRPD rights and existing commentary on the scope and potential impact of these rights. It will therefore need to be read in accordance with any future guidance issued by the Committee on the CRPD on Article 19 and/or related CRPD articles.

The full text of Article 19 is set out on the following page.

**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.*

Thus, Article 19 is very broad in scope. It includes three clear requirements. States must:

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

However, the reality for people with disabilities in many parts of the world is very different to the vision articulated by Article 19. This is because many continue to be placed in institutions rather than being given the support that they need to engage in community life as others do.

*The Institutionalization of People with Disabilities: Contrary to the CRPD*

The practice of institutionalizing people with disabilities, often for life, is still prevalent in many parts of the world, including parts of Europe. 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.

A common response by governments to such concerns is to attempt to improve the 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. 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 Supports to Promote Social Inclusion*

A primary reason for the institutionalization of people with disabilities is the severe lack of support in local communities that would enable them to live in their own homes or with their families. This is often exacerbated 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. Thus, although many governments have policies that seek to promote the human rights and social inclusion of persons with disabilities, progress in developing alternatives to institutionalization is painfully slow.

The lack of community-based services also impacts upon people with disabilities who remain with their families. 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. The emphasis of community-based services must be to enable people with disabilities to participate in community life as equal members of society.

### *Article 19 and the Closure of Long-Stay Institutions*

Although Article 19 makes no specific reference to the need to close long stay institutions, (this process is often referred to as “deinstitutionalization”) its provisions make clear that their closure is required, together with the development of community-based services alternatives. This is because the emphasis of Article 19 is on full inclusion and participation in the community.

Article 19 specifically requires States to ensure that persons with disabilities have access to community services that support their social inclusion and “prevent isolation or segregation from the community.” Such an objective 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. 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.

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 essential if States are to meet their obligations under Article 19 of the CRPD. Such services should be designed to enable each person to participate in community life.

## Action to Implement Article 19: A *Community for All* Checklist

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. The *Community for All* Checklist below suggests 10 areas that will need to be addressed when planning how to implement Article 19. Its focus is 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 the ten *Community for All* action points is provided below, including an explanation of how these points relate to the rights and obligations under the CRPD.

**1. Commit to transforming the system from institutional services to community-based services:** Although 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 continued 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 support 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.

**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”):**

Article 19 provides for the “equal right of all persons with disabilities to live in the community, with choices equal to others.”

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

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

In order to translate their commitment to establishing alternatives into concrete action, States must establish clear action plans. Given the complexities inherent in such systemic change, such plans will be essential. These plans should address specific actions that will be necessary to meet the requirements of Article 19.

- 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” (Office of the High Commissioner for Human Rights).<sup>2</sup>
- “Ideally, the transition from institutions from 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.”<sup>3</sup>

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

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<sup>2</sup> 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. 50

<sup>3</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham, J Deinstitutionalisation and community living – outcomes and costs (2007) Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent; p. 97

### **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 of cases of re-institutionalization (for example identifying and taking action to address) and reflecting review outcomes in relevant legislation, policy, and practice.

- 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. 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 (See Article 4, see also articles 3, 4(3), 26(1)(b) and 33(3).)

States will therefore need to create systems for involving people with disabilities and their families in three main areas:

- General measures for participation as required under the CRPD.
- Involvement in the process of implementing Article 19.
- Feedback on the quality of services provided to people with disabilities.

- 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 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.”<sup>4</sup>

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

This review should be part of the comprehensive review required under the CRPD (see Article 4(1)(b)). The legal and policy review in relation to Article 19 will need to be wide-ranging since it 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, the provision of goods and services)
- Monitoring of institutions and handling of complaints

The review of legislation is another area in which the CRPD requires the participation of civil society organizations and in particular organizations of people with disabilities.<sup>5</sup> Two important points will also 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.
- *Accessibility:* Article 49 of the CRPD requires that the CRPD is made available in accessible formats.

## **7. Review existing services for people with disabilities:** The review of services for people with disabilities covers two main areas:

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<sup>4</sup> 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 2009CRPD/C/2/3, 19

<sup>5</sup> 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. 31

- *Access to a range of community support services:* 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 the development of community-based services as alternatives to institutional services is crucial to States’ compliance with Article 19. Without such services people with disabilities have no real choice about where they live.

*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.<sup>6</sup>

**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. This action point is therefore an important aspect of the work to monitor and ensure the implementation of the CRPD. Examples of questions to be considered in this area are as follows:

- Is the use of public funds and/or donor funding to build new institutions or renovate existing institutions prohibited?
- 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:** 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 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.”<sup>7</sup>

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<sup>6</sup> This is defined in Article 2 CRPD

<sup>7</sup> Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study, 2007 Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent; p. 94

- “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.”<sup>8</sup>

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

The Office of the High Commissioner for Human Rights suggests that States can develop a plan of action which would cover the following:

- A clear timeframe for implementing the right(s)
- Time-bound benchmarks of achievement
- Indicators of success<sup>9</sup>

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<sup>8</sup> 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

<sup>9</sup> United Nations, Monitoring the Convention on the Rights of Persons with Disabilities, page 29