

**Human Rights Watch Submission**

**to the Office of the High Commissioner for Human Rights**

Thank you for the opportunity to submit our comments in advance of the Office of the High Commissioner for Human Rights (OHCHR) study on the right to live in the community for persons with disabilities. Human Rights Watch welcomes and strongly supports the OHCHR’s interest in examining the right to live in the community for persons with disabilities.

This submission is based on research and advocacy conducted by Human Rights Watch Russia, Ghana, Croatia, Peru, and India, in particular our reports[: *Barriers Everywhere: Lack of Accessibility for People with Disabilities in Russia*](http://www.hrw.org/reports/2013/09/11/barriers-everywhere-0) (September 2013),[[1]](#footnote-2) [*“Like a Death Sentence”: Abuses against Persons with Mental Disabilities in Ghana”*](http://www.hrw.org/reports/2012/10/02/death-sentence-0) (October 2012),[[2]](#footnote-3) and [*“Once You Enter, You Never Leave”: Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia*](http://www.hrw.org/reports/2010/09/23/once-you-enter-you-never-leave-0) (September 2010),[[3]](#footnote-4) and our ongoing monitoring of the right to live in the community for persons with disabilities. We highlight areas of concern and good practices in implementation of article 19 of the Convention on the Rights of Persons with Disabilities (CRPD), focusing on the following issues:

* Legal reforms
* Access to the environment and services to enable independent living and inclusion in the community
* Scope of deinstitutionalization plans
* Good practices of living independently in the community and community participation
* Data about living in the community

This document underscores several concerns that figured most prominently in our research, and that significantly influenced the degree to which persons with disabilities are able to exercise their right to live in the community. It does not attempt to review every aspect of this right.

**1. Legal Reforms**

Article 19 of the CRPD calls for governments to “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.”[[4]](#footnote-5)

One of the key challenges in upholding article 19 is the continued denial of legal capacity for people with disabilities. Legal capacity or the right to make one’s own decisions is closely linked with the right to live in the community with equal choices to others. While article 12 of the CRPD sets out that all persons with disabilities shall “enjoy legal capacity on an equal basis with others in all aspects of life,”[[5]](#footnote-6) many countries around the world continue to have incapacity and guardianship laws or practices that strip people with disabilities of their legal capacity, endowing a guardian, or simply a relative, doctor, or judge with the right to make their decisions. This denial or restriction of legal capacity can mean persons with disabilities no longer have the choice of or control over whether to live in the community, thereby effectively stripping them of their right under article 19 of the CRPD to “choose their place of residence and where and with whom they live.”[[6]](#footnote-7) Denial of legal capacity can result in a guardian making the decision to institutionalize a person with a disability. For example, in Croatia, guardians have the right to make the decision on where and with whom people stripped of legal capacity can live. A guardian can choose, against the will of the individual and without a court’s approval, to institutionalize an individual, place them in foster family for adults, or community housing. In Croatia, even when individuals do consent to living in an institution or adult foster home, that individual would have little choice regarding the type of service received – an integral part of the right to live in the community.[[7]](#footnote-8) Despite ongoing reforms to deinstitutionalize persons with disabilities in Croatia, people with disabilities living in institutions who have been stripped of their legal capacity still require the consent of their guardian to leave the institution or facility and move into the community.

In Ghana, individuals with psychosocial disabilities are routinely institutionalized against their will by family members or the police, and denied the opportunity to oppose or appeal their confinement.[[8]](#footnote-9) Ghana’s Mental Health Act of 2012 maintains a guardianship program that strips legal capacity from individuals with psychosocial disabilities, and also contains provisions that allow for the institutionalization of persons with psychosocial disabilities without their consent.[[9]](#footnote-10)

Similarly, in India, the Mental Health Act of 1987 allows a family member or guardian to admit a relative to an institution without their consent or any judicial review for up to 90 days at a time. The police also detain people with psychosocial or intellectual disabilities found wandering the streets if they have reason to believe them to be “dangerous” or incapable of taking care of themselves. These individuals are then admitted to these institutions through court orders with little possibility to appeal the decision. They are unable to leave the institution and can often stay there for life if no family member comes to take them home.

To ensure the right to live in the community, governments are obligated not only to recognize the right to legal capacity for all persons with disabilities on an equal basis with others but also provide accommodations and access to support with decision-making, where necessary, to exercise it. Legal reforms should also establish the right to live in the community, in line with the CRPD, with time-bound plans for establishing community-based living arrangements and support.

**2. Access to the environment and services to enable independent living**

For people with disabilities to participate fully and live independently in society, governments should strengthen or develop inclusive and accessible services. An integrated, holistic approach to such services should take into account the many aspects of people’s lives to enable people with disabilities to enjoy full inclusion in their communities. As one Moscow-based disability rights activist told Human Rights Watch, “Accessibility is a chain. If one link doesn’t work, then the whole thing doesn’t work.”[[10]](#footnote-11)

The CRPD obligates governments to ensure “[c]ommunity services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”[[11]](#footnote-12) Barriers to the physical environment, transportation, employment, and health care isolate persons with disabilities and prevent them from living in an inclusive community. Inaccessibility to the outside world is a key component of persons with disabilities not having access to community living.

Human Rights Watch research in Russia uncovered numerous barriers to living in the community for persons with disabilities. People with disabilities that we interviewed throughout Russia encountered inaccessible housing, government buildings, private businesses, healthcare facilities, and public spaces such as street crossings and sidewalks. In the most serious cases, people were almost completely confined to their homes due to a lack of basic accommodations to allow them to enter and exit their apartments and apartment buildings, many of which were buildings owned and maintained by city governments. Such confinement of people with physical disabilities to their homes severely limits their possibilities to work, go to school, obtain necessary medical or other services, socialize, or attend cultural events.[[12]](#footnote-13) Those who are able to leave their homes more easily face other obstacles in public spaces – such as stairs, narrow doorways, or cars parked in front of accessible entrances – preventing them from fully participating in society and participating in even the most basic daily tasks, such as going to the grocery store. People with disabilities also face barriers in accessing the transportation services provided in various cities throughout Russia. For example, not every Russian city has accessible buses.[[13]](#footnote-14) Similar problems of inaccessible infrastructure exist in countries around the world and are not unique to Russia.

Inability to access healthcare and rehabilitation facilities and services in the community can also interfere with a person’s right to live in the community, pressuring persons with disabilities to depend on institutional living to ensure access to appropriate health care. Our research indicated that the obstacles to obtaining health care in the community in Russia include difficulty in accessing healthcare clinics and diagnostic equipment and a lack of rehabilitation facilities and specialists in or near communities. People with sensory disabilities lack access to emergency services and face difficulty in making appointments.[[14]](#footnote-15)

In Croatia, the social protection system works to undermine the right of people with disabilities to choose community-based housing. In particular people with disabilities who pursue a full-time job are ineligible for community-based housing.[[15]](#footnote-16) Access to health care in the community also is a challenge for many persons with disabilities who choose to live in the community, with persons with intellectual disabilities living in the community usually having to go to see doctors at an institution. The Croatian Ombudswoman for Persons with Disabilities has documented that not even minimal progress has been made in development of outpatient treatment and improving the quality of health care for people with psychosocial disabilities in the community, which leads to multiple hospitalizations.[[16]](#footnote-17) Croatia’s personal assistance program that is designed to help persons with disabilities in their home, to facilitate participation in the community and help with financial matters, continues to benefit only persons with severe *physical* disabilities.[[17]](#footnote-18)

Article 19 of the CRPD requires governments to enable persons with disabilities to live independently and to participate and be included fully in their communities, including by guaranteeing their right to access services and facilities available to the general population on an equal basis with others. Without equal access to services and facilities, persons with disabilities have a more difficult time living in the community.

**3. Scope of deinstitutionalization plans**

Article 19 of the CRPD includes the right to access a range of in-home, residential, and other community-based services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. More broadly, the CRPD should be applied to all persons with disabilities without discrimination. However, Human Rights Watch is concerned that deinstitutionalization may be limited to people with certain types of disabilities in certain types of living arrangements.

For example, in Croatia, the government’s plan to enable persons with disabilities to live independently is limited in scope and does not encompass persons with intellectual or psychosocial disabilities who live in privately run but state-funded institutions or psychiatric hospitals,[[18]](#footnote-19) denying them the choice of where and how to live on the basis of where they are institutionalized. The plan also does not include persons with intellectual or psychosocial disabilities who are placed in so-called “family homes,”[[19]](#footnote-20) designed for up to 20 people and run by private individuals without adequate qualifications and training, and foster families where adults with disabilities are placed without their consent and with limited interaction with the community.[[20]](#footnote-21) The Law on Social Welfare considers family homes and foster homes for adults as non-institutionalized community living arrangements, but Human Rights Watch’s research found that they might amount to institutionalization if residents are not placed there by choice, they are closed to outsiders, and they restrict interaction between residents and the community.[[21]](#footnote-22) According to the national Master Plan, the Croatian government considers these homes as *preferred* forms of non-institutionalized community living arrangements, creating a real risk that people with disabilities will be moved from larger institutions into these homes without consent.[[22]](#footnote-23)

Individuals with intellectual or psychosocial disabilities who live in institutions that are part of Croatia’s deinstitutionalization plan also face barriers to their right to independent living and community participation. First, they are subject to an assessment by institution staff as to whether an individual is “ready to live in the community.”[[23]](#footnote-24) Persons with disabilities have the right to choose their place of residence and should not be obliged to live in a particular living arrangement because they did not pass the “readiness” test. Assessing an individual’s needs and strengths should serve only as an assessment of the kind of support and assistance that is necessary to make available to the person for them to exercise their choice (“individual planning” – see below). Secondly, a significant majority of persons with disabilities in Croatian institutions have been stripped of legal capacity under the Croatian legal capacity regime, granting guardians the power to take decisions on where and with whom those people with disabilities live. Finally, limited community housing and support further hampers their right to choose where and with whom to live. Persons with psychosocial or intellectual disabilities in Croatia told Human Rights Watch that they have no real choice in choosing their living arrangements once they leave institutions: due to limited housing and support options, people who have moved out of an institution usually live in community living arrangements established and monitored by the institution. Furthermore, financial resources restrict the ability of persons with intellectual or psychosocial disabilities to live independently. Those who do live independently have limited access to daily living support – such as entitlements (financial assistance) or in-home assistance (service of help and care at home).

**4.** **Good practices of living in the community**

Human Rights Watch has documented several positive examples of progress toward living in the community. Creating more community-based services, while also eliminating physical barriers to living in the community, are good alternatives to institutional care and empower persons with disabilities by providing them with greater agency and freedom to realize their potential as human beings. It also creates greater awareness of their needs within communities and reduces the stigma, discrimination, and violence to which they are often subjected.

The following examples of community-based support and services from Croatia and India illustrate how people with disabilities are able to exercise their right to live in the community. Programs that provide support, when necessary, particularly in transitioning persons with disabilities from an institutional setting to living in the community are key in ensuring that persons with disabilities are fully integrated in the community.

The Croatian government has made some progress in fulfilling the right to community participation and independent living. In 2011, Croatia adopted a national Plan for Deinstitutionalization and Transformation of Social Welfare Homes, and, two years later, in July 2013, two of the largest institutions in Croatia began the deinstitutionalization process, finding homes for people with intellectual or psychosocial disabilities. Another 11 state institutions, out of 28, followed. Currently, 458 persons with intellectual disabilities and 96 persons with psychosocial disabilities have moved out of institutions and live in the community.

For example, in 2012, the Home for Mentally Ill Adults Osijek, a social welfare home for adults with psychosocial disabilities in Osijek, Croatia, started the process of deinstitutionalization. By August 2014, 23 people with psychosocial disabilities had left the institution and were living in several apartments in Osijek. Some of these individuals told Human Rights Watch that they live in suitable homes, feel included in the community and have part-time jobs and assistants who support and help them. As of August 2014, 150 people remain institutionalized, out of which 23 people are to move out by the end of 2014 and another 70 people are to move out to community living arrangements with the help of the Open Society Foundations.[[24]](#footnote-25)

Human Rights Watch visited the institution and some of the apartments where former residents of the institution now live. Ladislav Lamza, director of the institution, told Human Rights Watch about the transition process and how the involvement, from the very beginning of the persons concerned, was the key to success. Lamza told Human Rights Watch how persons with psychosocial disabilities, who have been denied the right to live in the community for decades – some having spent up to 20 years in the Osijek institution – and restricted in all areas of life, were asked, encouraged and empowered to be fully included in the development of the deinstitutionalization process. The deinstitutionalization process of the Osijek institution developed as a program called “I, Just Like You,” designed to reduce and eliminate the established differences between a person with a psychosocial disability who lived in the institution, the service provider, and the community itself. This program is the voice of the person with psychosocial disability saying: “I, just like you have choices and I can reach my goals with the help of my service.”

Each individual spends around six months in the program preparing for life in the community. During this time, institution staff work with the individual to identify their needs, strengths, life goals and plans, which includes working with an individual on how, where and with whom they want to live and what support they need. This is called "individual planning" and is undertaken with an individual and their family while still in the institution. This also includes preparing individuals for life in the community, by building skills people have not had the chance to attain by living in an institution, skills other people take for granted: cooking, housekeeping, personal hygiene, and even social skills.

For this purpose, the Home for Mentally Ill Adults Osijek built a mock apartment where people learned how to cook, do dishes, wash, and iron their clothes. Once individuals have moved to community-based housing, institution staff provide regular support services (such as dealing with financial matters, facilitating participation in the community, helping with public transportation, facilitating access to community health services) to meet the need of individuals. Service planning and delivery is responsive to diversity in individuals.

In India, several nongovernmental organizations (NGOs) run community support and independent living initiatives, and have implemented creative and innovative models to provide essential services to persons with disabilities. For example, the Banyan, an NGO based in Chennai, helps persons with psychosocial or intellectual disabilities who cannot return to their families to take steps towards progressive independence through the formation of self-help groups and supported living, including a community living project that allows 70 people to live and work together in community-based housing.

Another Indian NGO, Iswar Sankalpa, has started a night shelter to support women, including those with psychosocial or intellectual disabilities, who are vulnerable to violence, particularly sexual abuse, on the streets. Once these women are ready to move out, the shelter either restores them to their families or helps them resettle in the community. The shelter focuses on rehabilitating women through vocational and income generating activities. Social workers from the shelter have also created an innovative local community support system for women who come to the shelter; they try to identify caregivers who can help keep a look out for women on the streets, for example, a local street vendor who can alert the shelter if a woman needs additional support.[[25]](#footnote-26)

**5. Data about living in the community**

Human Rights Watch has found through its research in Russia, Ghana, India, and Croatia that there is a serious lack of disaggregated data regarding people with disabilities living in the community. For example, Ghana has very little data on how many persons with psychosocial disabilities live within the country, and how many of these persons reside in institutions or other segregated settings such as “prayer camps” (spiritual healing centers).[[26]](#footnote-27) The lack of data makes it even more difficult to address gaps in community-based services for persons with psychosocial disabilities as it is unknown how many people need these services. Similar gaps exist in other countries, such as India.

**Conclusion and recommendations**

To realize fully the right of persons with disabilities to live in the community worldwide, governments and their development partners should adopt a comprehensive and holistic approach, in consultation with people with disabilities and disabled persons’ organizations (DPO). Central to this approach is the creation of community-based services and reasonable accommodations enabling persons with disabilities to realize their right to live in the community on an equal basis with others.

Human Rights Watch recommends that governments should:

* Immediately review and revise laws and regulations in line with article 19 of the CRPD.
* Carry out legal reforms to:
  + Recognize the legal capacity of all persons with disabilities on an equal basis with others and the right to exercise it. Provide appropriate accommodations and access to support where necessary to exercise legal capacity.
  + Replace regimes of guardianship and substitute decision-making with a system of supported decision-making that respects the person’s autonomy, will, and preferences.
  + Ensure that any legislative measures regarding legal capacity are not directed at persons with disabilities but apply on an equal basis to all persons.
  + Consult widely with persons with disabilities, particularly those affected by deprivation of legal capacity, and DPOs in the reform process.
* Develop a plan for deinstitutionalization based on the values of equality, autonomy and independence, and inclusion for persons with disabilities; and prohibit the forced institutionalization of any person simply on the basis of disability.
* Create a body composed primarily of persons with disabilities and other experts to monitor and assess the effectiveness of community-based support services. Incorporate the conclusions of this body into future regulations.
* Provide adequate and appropriate community-based services that provide assistance to persons with disabilities living within the community by working with DPOs and other organizations.
* Reduce barriers to living in the community for persons with disabilities. This should include:
  + Developing a time-bound plan to ensure accessible transportation.
  + Consulting with representatives from DPOs, including persons with intellectual or developmental disabilities, regarding the minimum requirements to establish an inclusive educational environment and inclusive public spaces, such as accessible parks, museums, recreation centers, and hospitals.
  + Working with DPOs and other allied organizations to launch nationwide social advertising campaigns that highlight the diverse personalities, interests, and social contributions of persons with all types of disabilities.
* Collect annual statistics on the number of people with disabilities disaggregated by gender, age group, and specific disabilities. Ensure that these statistics include the number of people with disabilities living in the community, institutions, and other facilities.

We hope this submission is useful to OHCHR as you prepare a study on the right to live in the community for persons with disabilities. We look forward to continuing to support the work of OHCHR in promoting strong and effective implementation of the CRPD.

1. Human Rights Watch, *Barriers Everywhere: Lack of Accessibility for People with Disabilities in Russia*, September 2013, http://www.hrw.org/reports/2013/09/11/barriers-everywhere-0. [↑](#footnote-ref-2)
2. Human Rights Watch, *“Like a Death Sentence”: Abuses against Persons with Mental Disabilities in Ghana,”* October 2012, http://www.hrw.org/reports/2012/10/02/death-sentence-0. [↑](#footnote-ref-3)
3. Human Rights Watch, *“Once You Enter, You Never Leave”: Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia,* September 2010, http://www.hrw.org/reports/2010/09/23/once-you-enter-you-never-leave-0. [↑](#footnote-ref-4)
4. International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, annex, I U.N. GAOR (No. 49) at 65, U.N. Doc. A/61/49 (2006), entered into forced May 3, 2008, art. 19. [↑](#footnote-ref-5)
5. Ibid., art. 12. [↑](#footnote-ref-6)
6. CPRD, art. 19. [↑](#footnote-ref-7)
7. Human Rights Watch, *Once You Enter, You Never Leave*, p. 26. [↑](#footnote-ref-8)
8. Human Rights Watch, *Like a Death Sentence*, p. 38. [↑](#footnote-ref-9)
9. Mental Health Act 2012, arts. 68-70, http://www.thekintampoproject.org/storage/Mental%20Health%20Act%20846%20of%202012.pdf. [↑](#footnote-ref-10)
10. Human Rights Watch, *Barriers Everywhere*, p. 7. [↑](#footnote-ref-11)
11. CRPD, art. 19. [↑](#footnote-ref-12)
12. Human Rights Watch, *Barriers Everywhere*, p. 20. [↑](#footnote-ref-13)
13. Ibid., pp. 33-35. [↑](#footnote-ref-14)
14. Ibid., pp. 53 -59. [↑](#footnote-ref-15)
15. Human Rights Watch interview with Neda Mimščević, legal expert, Association for Promotion of Inclusion, Zagreb, May 16 2014. [↑](#footnote-ref-16)
16. Ombudswoman for persons with disabilities of the Republic of Croatia, *Izvjesce o radu 2013. Godine [*Annual Report 2013], p. 19. [↑](#footnote-ref-17)
17. Human Rights Watch e-mail correspondence with Zvjezdana Bogdanovic, head of the Department of the Persons with Disabilities and Older People of the Ministry for Social Policy and Youth, July 10, 2014. [↑](#footnote-ref-18)
18. According to the official data obtained from the Croatian Ministry of Social Policy and Youth as of July 2014, there are 13 non-state institutions that provide housing for persons with intellectual disabilities, and 11 non-state institutions that provide housing for persons with psycho-social disabilities. [↑](#footnote-ref-19)
19. According to the data obtained from the Croatian Ministry of Social Policy and Youth, there are 3 family homes for persons with physical and intellectual disabilities, and 20 family homes for adult persons with psychosocial disabilities. [↑](#footnote-ref-20)
20. In Croatia there are 298 foster families for adult persons with physical and intellectual disabilities and 272 foster families for adult persons with mental health problems. [↑](#footnote-ref-21)
21. Law on Social Welfare, Official Gazette, No. 157/13 http://www.zakon.hr/z/222/Zakon-o-socijalnoj-skrbi (accessed July 21, 2014), art. 74. Human Rights Watch, “*Once You Enter, You Never Leave”: Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia*, September 2010, http://www.hrw.org/reports/2010/09/23/once-you-enter-you-never-leave. [↑](#footnote-ref-22)
22. Croatian Ministry of Health and Social Welfare, Odluka o planu deinstitucionalizacije i transformacije domova socijalne skrbi i drugih pravnih osoba koje obavljaju djelatnost socijalne skrbi u Republici Hrvatskoj 2011.-2016. (2018) [Plan for Deinstitutionalisation and Transformation of Social Welfare Homes], http://www.propisi.hr/print.php?id=10984 (accessed July 20, 2014). [↑](#footnote-ref-23)
23. Human Rights Watch interview with Sanjica Grbavac, director of the Center for Rehabilitation Stančić, Dugo Selo, May 20, 2014. [↑](#footnote-ref-24)
24. Email communication with Ladislav Lamza, director of the Home for Mentally Ill Adults Osijek, August 13, 2014. [↑](#footnote-ref-25)
25. Human Rights Watch, *Like a Death Tunnel*, p. 61. [↑](#footnote-ref-26)
26. Human Rights Watch, *Like a Death Sentence*, p. 86. [↑](#footnote-ref-27)