



“It is My Dream to Leave This Place”

Children with Disabilities in Serbian Institutions

Copyright © 2016 Human Rights Watch

All rights reserved.

Printed in the United States of America

ISBN: 978-1-6231-33603

Cover design by Rafael Jimenez

Human Rights Watch defends the rights of people worldwide. We scrupulously investigate abuses, expose the facts widely, and pressure those with power to respect rights and secure justice. Human Rights Watch is an independent, international organization that works as part of a vibrant movement to uphold human dignity and advance the cause of human rights for all.

Human Rights Watch is an international organization with staff in more than 40 countries, and offices in Amsterdam, Beirut, Berlin, Brussels, Chicago, Geneva, Goma, Johannesburg, London, Los Angeles, Moscow, Nairobi, New York, Paris, San Francisco, Sydney, Tokyo, Toronto, Tunis, Washington DC, and Zurich.

For more information, please visit our website: <http://www.hrw.org>



JUNE 2016

ISBN: 978-1-6231-33603

“It is My Dream to Leave This Place”

Children with Disabilities in Serbian Institutions

Map	I
Summary	1p
Life in Institutions.....	6
Obligations	10
Way Forward	12
Methodology.....	15
Institutionalization in Serbia	18
National Framework and Initiatives	18
Small Group Homes	21
Family Outreach Service	24
Illusion of Decline; Increase in Admissions	25
More Investments in Institutions Instead of Community Care.....	28
Serbia’s International and National Legal Obligation to Ensure the Right of a Child to not be Separated from His or Her Family	30
The Path to Institutionalization	33
Undue Pressure on and Lack of Information to Parents	33
Lack of Community-Based Services.....	36
Lack of Inclusive Education.....	41
Poverty and the Broken Foster Care System.....	45
Abuse of Children with Disabilities in Institutions.....	50
Segregation and Seclusion	50
Neglect.....	52
Lack of Privacy for Personal Care.....	54
Insufficient Safeguards Against Abusive Use of Restraints and Physical and Psychological Violence	55
Right to be Free from Violence and Neglect.....	56
Involuntary and Potentially Inappropriate Medical Treatment	58
Right to education	70

Limited Freedom of Movement	74
Denial of Legal Capacity.....	75
Right to Legal Capacity for Adults with Disabilities	77
Recommendations.....	80
To the Serbian Government, Including the Ministries of Social Policy, Health, Education, and Finance	80
To the European Union	85
To Serbia’s International Partners	85
Acknowledgments.....	87
Appendices	89

• Institutions in Serbia where children with disabilities live



Summary

If I would touch her little hands or feet, she retracted, like a turtle inside of her shell. For about two or three months we struggled to establish some sort of physical contact. The first time she rested her head on my shoulder was three months after coming to our home. It was the most beautiful thing that happened.

—Suzana, foster parent of Marina, a 4-year-old girl with developmental disabilities, who was 10-months-old when she left an institution to live with her foster family

Julija, a 4-year-old girl with a disability, was born in Belgrade, Serbia's capital, in 2012, to proud parents Ivica and Jasmina. However, after the birth, Julija was not brought in to her mother as other children were. Instead, as Julija's mother Jasmina explained, "The nurses started consoling me by saying: 'You will have another child. You will have another child, don't cry.' Julija was written off immediately."

For the first couple of days, despite repeated inquiries, Jasmina and Ivica were not given any information about their daughter's health and well-being. Then a doctor told them Julija has a rare genetic condition called Apert Syndrome – which results in vision and hearing loss, difficulty breathing and eating, cognitive delays, and webbed fingers and toes. The doctor and nurses told them that it would be best to leave Julija there in the maternity ward and for her to be placed in an institution for children with disabilities. They did not want to do that.

Instead Ivica and Jasmina travelled across Serbia for specialist appointments and surgeries to get Julija the very best treatment possible. However, they were continuously advised by health care professionals that it was best for their daughter to live in an institution:

One doctor told us, 'It will be a torment for you and you don't know if you will receive anything in return.' Medical nurses would tell us, 'This is best for you and for her. It is better for her to be with children that are like her.'

With no community support and services available, especially after a critical head surgery, they made the difficult decision to place their three-month-old baby girl in an institution for children with disabilities in Belgrade, believing they were doing what was best for their child. However, after Julija was placed in the institution, her parents began noticing the deterioration of her well-being and development:

We went to visit her and nothing remained of that child who used to smile and cackle. She had a lost look in her eyes, she visibly lost weight, she was sad in a way. I don't know whether it is possible for a three-month-old child to feel that - a lack of parental love, but... it was as if she had sunken. And shortly thereafter she had an infection and stayed in the hospital, barely making it out alive from pneumonia, and so on.... But it really was a visible change. Not only I as her mother, but my cousin who was with me, she noticed the same. That she was no longer the child she used to be.

Julija spent 10 months in the institution between May 2012 and March 2013 with visits home depending on her health condition:

We wanted her to be home as much as possible, but sometimes that was just not possible because of her health condition. Doctors and staff at the institution supported us in these efforts because they could see that Julija felt better – and so did we.

Jasmina and Ivica explained how doctors and social workers from the institution were the only point of reference during this difficult period and it was the only place they could turn to for help and support.

Jasmina and Ivica then decided to bring Julija back home for good. Ivica described the experience: “When Julija is at home with us, she is one child, and when she is in an institution, she is a different child. She has made much more progress (at home), in terms of her weight and everything else. Her intellectual development, too.” Julija’s parents now know that many people with Apert Syndrome can lead a life like others, including going to school and getting a job.



Julija Čuković, who spent ten months of her life in an institution, at home in Kragujevac with her parents, where she enjoys to play with her younger sister, also in the photo. © 2016 Zoran Stamenković

However, the battle is only beginning: Julija needs continuous health care for her breathing, vision, ability to speak, all of which is lacking in Serbia.

Across Serbia, children with disabilities live away from their families in large residential institutions for children with disabilities with little to no personal attention, in most cases leading to children's stunted physical, emotional, and intellectual development. The system currently favors institutionalization rather than support for families.

This report, based on 118 in-depth interviews with children with disabilities and their families, disability advocates, staff of institutions, and government officials, documents a

range of issues that children with disabilities experience in institutions in Serbia (an aspiring member of the European Union), which leads to multiple violations of their rights. These issues include segregation, neglect, including a failure of guardians to play a meaningful role in the children's lives, lack of privacy, use of potentially inappropriate medical treatment and failure to provide information about or seek consent for treatment, lack of access to education, limited freedom of movement, denial of legal capacity upon reaching adulthood, among others.

This report also highlights some promising practices for services and supports within Serbia, which should be scaled up to ensure that children are able to live and thrive in their communities.

Over the past several years, the Serbian government has introduced strong legal and policy measures to safeguard every child's right to live in the community and right to family life. For example, the Ministry of Labour, Employment, Veteran and Social Policy has developed and strengthened alternative care arrangements in the community for children separated from their families, such as foster care. In 2011, the government adopted a prohibition on placing children under the age of three in institutions without "justified reasons," and even then, generally for no longer than two months. In 2013, UNICEF developed family outreach services in the cooperation with the Ministry of Labour, Employment, Veteran and Social Policy to support families, including families of children with disabilities, where there is a risk of separation of children.

Despite this progress, lack of health care and support services in the community, poverty, stigma, discrimination, and social exclusion means that children with disabilities continue to be placed in institutions, even though many have a living parent. Medical staff, including doctors, also often advise parents to institutionalize their child with a disability.

Serbia continues to invest in construction and renovation of institutions. In March 2014, the government opened a newly built institution for children and young people with disabilities in Šabac, a city in western Serbia. At the same time, there are almost no community-based support and services for children and their families. Where services do exist, they are limited in scope, outreach, and continuity.



A living room in Veternik Institution where children and adults with disabilities spend most of their days. There are no toys, education materials, or carpets on the floor. The only available source of stimulation is a TV attached to the wall. © 2015 Emina Ćerimović for Human Rights Watch

Children with disabilities in particular have been overlooked in national efforts to address the separation of children from their families; and children with disabilities continue to be significantly over-represented in residential care. Human Rights Watch found that the government continues to place even babies with disabilities in institutions, despite the 2011 prohibition.

In its 2012 state report to the United Nations Committee on the Rights of Persons with Disabilities, the government asserts a slight decline in the number of children with disabilities in institutions. However, this reports documents that the government's reported decrease in the number of children in institutions was because some children have simply reached the age of adulthood and are not counted as children anymore. After



A room in the Sremčica Home for children and adults with disabilities where 292 persons, including 49 children, with disabilities live. Up to 10 people live in one room. © 2015 Emina Ćerimović for Human Rights Watch

turning 18 years old, some children either continue to live within the same institution or are transferred to institutions for adults.

Life in Institutions

While the aim of placing children with disabilities in institutions is to protect them and provide them with “specialized” care, the reality is that children are placed in centralized residential homes with limited staff and personal contact, often far from their families and communities. This results in the arbitrary separation of children from their families and isolation from society. Most children with disabilities in Serbia who are placed in institutions as children, will continue to live in institutions for their whole lives. Existing

research demonstrates that institutionalizing children harms their health, development, and reduces future life chances.

In fact, institutions in Serbia struggle to provide the individual attention and care that children with disabilities need, and are instead places where children with disabilities experience neglect, abuse, overmedication, isolation, and are excluded from education, play, and their communities.

In three of the five institutions visited by Human Rights Watch, children with disabilities lived in the same room and wards as adults. Placement of children with unrelated adults is not only a violation of international standards, it places children with disabilities at a higher risk of violence and abuse.

Human Rights Watch also found that medication, including psychotropic medications, which is used on children with disabilities in institutions often as a means of dealing with behavioral issues, is dispensed with minimal oversight or review, without explanation of the purpose of the medication

to the children, and with a lack of clarity as to whose consent is required for the administration of medications. Human Rights



One of the isolation rooms in the Veternik institution. Isolation rooms are used to separate children and adults from other residents in cases of contagious diseases or until they “adapt” to the institution. © 2015 Emina Čerimović for Human Rights Watch

Watch has serious concerns about the appropriateness of some of the medications and how they are dispensed.

Children with certain disabilities, typically those who cannot walk and talk, are segregated in special wards within institutions, where they spend the majority of their days lying down with minimal interaction with others persons. The practice of keeping children with certain disabilities in such conditions is discriminatory, inhumane, and degrading.

Lack of sufficient personnel for the large number of children and adults, in particular those with higher support needs, means that individualized attention and care from caregivers inside institutions is a significant problem documented in all large institutions Human Rights Watch visited.

Legal guardians, appointed by the state to care for the child and ensure the child's best interests are respected in all instances, in most cases do not visit or interact with children who live in institutions. Limited or no contact with their legal guardians jeopardizes the child's right to be protected from abuse and neglect and the right to education and family life.

Most adults (including young people between the age of 18 and 26) with disabilities living in Serbian institutions are also deprived of legal capacity, or the right to make decisions about basic rights, and

VREME	AKTIVNOSTI
7:00 – 8:30	Ustajanje – lična higijena
8:30 – 9:30	Doručak, podela terapije, sređivanje kreveta
9:30 – 10:30	Aktivnosti sa decom – u dve grupe <ul style="list-style-type: none">• edukativne radionice u sobi za radnu terapiju• društveno-rekreativne aktivnosti u dnevnoj sobi
10:30 – 11:30	Aktivnosti sa decom <ul style="list-style-type: none">• individualni rad u sobi za radnu terapiju• Individualni pristup i druženje sa decom (u dnevnoj sobi, dnevnom boravku, MNRO, terasi, dvorištu...)
11:30 – 12:00	Užina
12:00 – 13:00	Fizioterapeut (dva puta nedeljno)
13:00 – 13:30	Priprema za ručak (pranje ruku, postavljanje obroka)
13:30 – 14:30	Ručak
14:30 – 15:30	Popodnevni odmor
15:30 – 16:00	Pripremne aktivnosti za radioničarski rad
16:00 – 16:30	Užina
16:30 – 17:30	Kreativna radionica (u sobi za radnu terapiju u dve grupe naizmenično)
17:30 – 19:00	Slobodne aktivnosti (šetnja, TV, čitanje bajke, sluš. muzike)
19:00 – 19:30	Priprema za večeru
19:30 – 20:30	Večera
20:30 – 21:00	Neformalno međusobno druženje
21:00 – 21:30	Priprema za spavanje
Nakon 21:30	Spavanje

A schedule of children with disabilities in one of the institutions Human Rights Watch visited. The schedule is the same each day, with 30-minute blocks of time allotted for meals, occupational therapy, hygiene, sleep, and leisure activities. © 2015 Emina Ćerimović for Human Rights Watch



Marina [pseudonym], a 4-year-old girl with developmental disabilities who spent ten months of her life in an institution, with her foster sister. © 2015 Jasenko Rasol for Human Rights Watch

placed under guardianship. The guardian – often nominated by the state – makes all decisions for them. For example, Human Rights Watch documented cases in which young women with disabilities deprived of legal capacity were subjected to invasive medical interventions, including termination of pregnancy, with the consent of the guardian, but without their own free and informed consent.

Children and young people with disabilities living in Serbian institutions have limited access to education and the vast majority of them are not enrolled in schools. Children who do receive education attend specialized schools exclusively for children with disabilities. In some cases teachers visit institutions to teach children in groups for a few hours a day. Day care centers, the most common community-based service provided for



Bathroom in the Stannica Home for children and adults with disabilities. There are no doors or means of privacy separating the toilets in the bathroom. There are no showers and children use the water hose when taking a bath. © 2015 Emina Čerimović for Human Rights Watch

children and adults with disabilities in Serbia, have become a substitute for schools for children and young people with disabilities who live in the community.

Obligations

Serbia is party to a number of human rights treaties, including the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC), the Convention Against All Forms of Torture and the European Convention on Human Rights (ECHR), and as such is obligated to protect the rights of children with disabilities and ensure their full participation in society. This includes ensuring no child is separated from his or her family on the basis of their disability. As a party to the Convention on the Rights of Persons with Disabilities the Serbian government is obligated to guarantee full inclusion

of children and young persons with disabilities into society, including by making progress on deinstitutionalization and improved support for children with disabilities living in the community. Serbia is further obliged to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis as others and the right to receive the support they need to make their own choices and to direct their own lives, whether in relation to medical treatment, family, parenthood and relationships, or living arrangements. As a party to the Convention on the Elimination of All Forms of Discrimination against Women, Serbia must not discriminate on the basis of gender, including with regards to access to health care and family planning.

In April 2016, the UN Committee on the Rights of Persons with Disabilities expressed serious concerns “about the number of children with disabilities living in institutions” and about the “very poor living conditions in institutions” in Serbia. The Committee urged Serbia to “deinstitutionalise children... and prevent any new institutionalisation of infants under the age of three,” and to “take immediate steps to ensure that all persons with disabilities have access to inclusive and quality... education.” The Committee also called on Serbia to protect persons with disabilities in all institutional settings from violence, abuse, and ill-treatment of any kind. It further urged Serbia to prohibit “all forms of coercive treatments against adults and children with disabilities and to replace its guardianship system for adults with supported decision-making regimes.

Serbia is a candidate for European Union (EU) membership. Under the Stabilization and Association Agreement, a key step toward EU accession, Serbia is expected to gradually bring its laws into conformity with those of the EU, including with respect to the treatment of persons with disabilities under chapter 24 of the EU Acquis. The Acquis is the body of common rights and obligations that is binding on all the EU member states.

The EU has taken a strong stance on Serbia’s problematic treatment of children with disabilities in institutions. Its 2015 progress report on Serbia urged authorities to prevent placement in institutional care by prioritizing family and parenting support services, expanding community-based services, and by ensuring more integrated service delivery. Serbia is also obligated to protect children with disabilities from all forms of violence and from torture or inhuman or degrading treatment. Serbian national law prohibits inhuman and degrading treatment and guarantees all citizens in state care the right to humane treatment.



A room in the Veternik Institution for children and adults with disabilities where 540 persons, including children with disabilities live. Up to eight people live in one room. © 2015 Emina Ćerimović for Human Rights Watch

Way Forward

Human Rights Watch calls on the Serbian government to take concrete steps to ensure that every child's right to live with their family or family-like environments is respected and implemented. The report calls on the government to develop a plan for the deinstitutionalization of children and the necessary services and support mechanisms in communities, focusing on the inclusion of children in all aspects of society.

As a matter of priority, the Serbian government should:

1. Prevent abuse

Serbia should immediately take steps to end neglect of children living in institutions and hold those responsible for treatment of children to account. Isolation, neglect, inappropriate psychiatric treatments (including the inappropriate use of psychotropic medications as a means of dealing with behavioral issues), and discrimination of children with disabilities in institutions should end. Serbia should take all effective and appropriate measures, including through ensuring effective oversight and review of the use of medications on children, and to abolish any treatment that is inconsistent with the right to health of children.

2. Prevent separation

The Serbian government should develop services in the community to prevent family separation. Services should include healthcare, inclusive and quality schools, financial assistance to families of children with disabilities, and parenting counseling, among others. Funding community care and support for children with disabilities in other countries has been shown to be more cost-effective in the long term than funding large-scale institutions.

3. Reunite families

The majority of children with disabilities in Serbian institutions have at least one living parent and reasons for separation include poverty, lack of access to health care, access to education, and undue pressure on parents by healthcare professionals to place their child with a disability in an institution. Many children can return to live with their birth families when the right community-based services have been put in place.

4. Provide alternative care

Where it is not possible to return to their birth families, including cases of abuse and neglect, children should be provided with an opportunity to live in family-like environment care with relatives, foster families or adoptive parents. These potential caregivers should be carefully screened, trained and monitored to ensure the placements is protective and in the best interest of the child. Agencies responsible for foster care should work on strengthening the birth families so they can meet their child's needs and be reunited.

5. Ensure inclusive education

Serbia has adopted strong legal and policy measures on inclusive education and should take immediate steps to implement them in practice to ensure children with disabilities have an equal opportunity and option to go to mainstream schools that are accessible, free of violence, and receive a quality education that addresses and accommodates their needs.

6. Protect the right to legal capacity

Serbia should replace its guardianship regime for adults with a system of assistance and support in decision-making that respects the autonomy, will, and preferences of the person with disability.

The government should implement the recommendations of the UN Committee on the Rights of Persons with Disabilities from April 2016.

The European Commission, as part of monitoring compliance with the EU accession requirements, should hold Serbia to its obligations to respect the human rights of persons with disabilities as a precondition for EU membership. In dialogues with Serbian authorities, EU representatives should stress the importance of respect for the absolute prohibition of neglect and discrimination against children with disabilities in Serbian institutions, and should continue to call on the Serbian government to deinstitutionalize children with disabilities.

Methodology

This report is based on field research carried out in Serbia for four weeks between October and December 2015. Additional interviews were conducted over the phone from January to March 2016.

Human Rights Watch researchers interviewed 48 children and young people with disabilities and their families. Out of this number, 11 were children under the age of 18, 30 were young people between 18 and 30 years old, 4 were birth parents, and 3 were foster parents of children with disabilities. 42 of the interviews were conducted individually; 6 individuals were interviewed in the presence of immediate family members or staff of institutions.

Human Rights Watch took great care to interview people in a manner that respected their rights and dignity, and ensured that the interviews took place in a location where the interviewee's privacy was protected.

In all cases, Human Rights Watch told interviewees they would receive no personal service or benefit and that the interviews were completely voluntary and confidential. Participants were informed that they could discontinue the interview at any time or decline to answer any specific questions without consequences. All interviews were conducted in Serbian or English, or were translated into English by an interpreter.

Unless otherwise noted, we have used pseudonyms for all children, young people, and their families in order to protect their privacy. In some cases we have concealed other details, such as the name of the institution where they live or the date of the interview. We have also withheld names and other details from some institution staff for their protection from possible reprisals. All interviews are on file with Human Rights Watch.

Human Rights Watch also interviewed officials at United Nations Children's Emergency Fund (UNICEF), the Delegation of the European Union, the Protector of Citizens (the Serbian Ombudsperson), the Commissioner for Equality, and staff members of various nongovernmental organizations (NGOs) and disabled peoples organizations (DPOs) in Serbia, including Mental Disability Rights International, the Centre for the Rights of the

Child, the National Mental Health Organization (MNRO), VelikiMali, the Network of Children in Serbia, Ideas Centre for Social Research, and the Grig Centre for Social Preventive Activities. Interviews were held with senior government officials in the Ministry of Labour, Employment, Veteran and Social Policy, the Ministry of Health, and the Ministry of Education. Human Rights Watch also interviewed directors of two Centers for Family Placement and Adoption in Belgrade and Niš, and met with the representatives of the Republic Institute for Social Protection.

Human Rights Watch visited five large social welfare homes¹ in Belgrade, in Sremčica, Veternik, Subotica, and Stamnica, and three small group homes for children and young people with disabilities in Belgrade, Niš, and Aleksinac. During our visits, we interviewed 42 current staff members (directors, social workers, medical and other staff). The Ministry of Labour, Employment, Veteran and Social Policy refused permission for Human Rights Watch to visit the institutions independently, and a representative from the ministry, was present during Human Rights Watch's visits to all institutions and small group homes as well as during interviews with directors of the institutions.

The representative from The Ministry of Labour, Employment, Veteran and Social Policy denied Human Rights Watch the opportunity speak privately to children, insisting that a child's guardian must be present. In such instances, Human Rights Watch agreed to have a guardian at the interview. However, the representative and institution staff stated that guardians often live far away from the institution and that it is difficult to secure their presence or their verbal permission. As a result, Human Rights Watch could not interview children in some of the institutions.

Human Rights Watch also spoke with 11 activists from local children's and disability rights NGOs in Serbia, one family outreach service coordinator and three family outreach workers. Human Rights Watch researchers also consulted international disability rights

¹ Zvečanska Center for Protection of Infants, Children, and Youth, Stamnica Home for children and adults with disabilities, Veternik Institution for children and adults with disabilities, Kolevka Home for children with disabilities and Sremčica Home for children and adults with disabilities. According to the institutions staff, as of October 2015, up to 540 people lived in Veternik Institution for children and adults with disabilities, including 59 children; 345 in Stamnica Home for children and adults with disabilities, including 22 children; 292 in Sremčica Home for children and adults with disabilities, including 49 children; 120 children with disabilities in Zvečanska Center for Protection of Infants, Children, and Youth; and 167 children with disabilities in Kolevka Home for children with disabilities. Up to 13 children and young people lived in small group homes.

experts at various stages of the research, including during the initial review of Serbia by the United Nations Committee on the Rights of Persons with Disabilities in April 2016 in Geneva, Switzerland.

As part of this research, we also reviewed a number of Serbian government policies and laws and relevant reports from United Nations agencies, the European Union and NGOs. On April 19, 2016, Human Rights Watch sent letters to the Ministry of Labour, Employment, Veteran and Social Policy, the Ministry of Health, and the Ministry of Education, setting out concerns about the abuses against children and young people with disabilities in Serbia. The Ministry of Education formally responded on April 28, 2016 and on May 19, 2016, and the Ministry of Health responded on May 9, 2016. Their response is reflected in this report. The English version of the letters are attached as an appendix to the report. The Ministry of Labour, Employment, Veteran and Social Policy did not provide a response in time to be included in this report.

In line with international instruments, the term “child” as used in this report refers to a person under the age of 18; “young people” refers to persons between the age of 18 and 30 years old.

Institutionalization in Serbia

The first information we received was that she has no chance for a long life and intellectual development and that it is best for us to leave her in the maternity ward and have her placed in an institution.

–Jasmina Čuković, mother of Julija, a 4-year-old girl with developmental disabilities²

I’ve been here since I was little.

–A 20-year-old young man with physical and intellectual disabilities living in Stamnica Home for Children and Adults with Disabilities³

National Framework and Initiatives

The Serbian government has taken some positive steps toward preventing the institutionalization of children. For example, the Ministry of Labour, Employment, Veteran and Social Policy has developed and strengthened alternative care arrangements in the community for children separated from their families, such as foster care. The United Nations Children’s Emergency Fund (UNICEF), supported primarily by the European Union and additionally by the Novak Djokovic Foundation,⁴ has developed family outreach services to support families where there is a risk of separation of children.

Despite this progress, Human Rights Watch research found that children with disabilities continue to be placed in institutions and the process of moving children out of institutions to community-based care has been limited and slow. There continues to be a lack of community support and services for children and their birth families to prevent

² Human Rights Watch interview with Jasmina and Ivica Čuković, Serbia, December 1, 2015.

³ Human Rights Watch interview with a 20-year-old man [name withheld], Serbia, October 21, 2015.

⁴ Novak Djokovic Foundation invests in early childhood education and support programs in Serbia. See more at: <https://novakdjokovicfoundation.org> (accessed May 17, 2016).

unnecessary family separations.⁵ According to the national Network of Organizations for Children in Serbia, a network of 75 civil society organizations for children, the number of children placed in formal care in Serbia is growing.⁶

Children with disabilities continue to be overrepresented in institutional settings. As many as 79.9 percent of children in institutions in 2014 in Serbia were children with disabilities, up from 62.5 percent from 2012.⁷ Most of these children have at least one living parent. In 2011, the government amended the Law on Social Protection to include a prohibition on placement in institutions for children under the age of three unless there are “justified reasons” and no longer than two months, except where the ministry responsible for social protection gives its consent.⁸ This law, however, does not explain what “justified reasons” are for which a child under the age of three can be placed in an institution.⁹ There are also no guidelines on the application of this provision. The 2006 Regulations on Removal of Irregularities in Placing Children and Youth in Institutions of Social Welfare¹⁰ only oblige the Centre for Social Work to consider the applicability of support services to birth families and the child, and provide the possibility of placing a child in foster care as an alternative form of protection, before deciding on placing a child in an institution.¹¹

⁵ Under the Convention on the Rights of the Child, Serbia is obliged to “ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.” See: Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A., Res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force September 2, 1990, art. 9.

⁶ Network of Organizations for Children in Serbia, Press release, “All children in Serbia are equal, but some are more equal than the others,” November 19, 2015, <http://zadecu.org/en/press-releases.php> (accessed April 15, 2016).

⁷ Republic Institute for Social Protection, Children in Social Welfare 2014 [In Serbian: Deca u sistemu socijalne zaštite], Belgrade, July 2015. p.39. (Available in Serbian at): <http://www.zavodsz.gov.rs/PDF/izvestaj2015/DECA%20U%20SISTEMU%20SOCIJALNE%20ZASTITE.pdf> (accessed May 1, 2016).

⁸ Law on Social Protection, Official Gazette of the Republic of Serbia, No. 42/2011, art. 52, (Available in Serbian at): http://www.paragraf.rs/propisi/zakon_o_socijalnoj_zastiti.html (accessed January 13, 2016).

⁹ A Human Rights Watch researcher was allowed to see a decision issued by the Ministry of Labour, Employment, Veteran and Social Affairs, giving the consent on the placement of a child. The decision explains how the Centre for Social Work had exhausted all other possibilities to provide a child with accommodation in less restrictive manner and should therefore be placed in an institution.

¹⁰ Ministry of Labour, Employment and Social Affairs, Regulations on Removal of Irregularities in Placing Children and Youth in Institutions of Social Welfare [In Serbian: Mere za otklanjanje nepravilnosti u vršenju poslova smeštaja dece i omladine u ustanove socijalne zaštite], No. 560-03-619/2006-14. November 3, 2006.

¹¹ Ibid. Section III, Para. 3.

While the amendments in Law on Social Protection have led to a decrease in the placement of babies in institutions, Human Rights Watch found that babies with disabilities under the age of three are still being placed in institutions. The Republic Institute for Social Protection points out that 48 children with disabilities under the age of three lived in orphanages in 2014.¹² According to the staff of Zvečanska Center for Protection of Infants, Children and Youth, Belgrade, as many as nine children, including five babies with disabilities, were placed in the institution in 2015.¹³ According to local experts and UNICEF, babies continue to be placed in institutions directly from maternity wards.¹⁴

Research has shown that institutionalization of babies harm their early brain development, can result in developmental delay and permanent disability, and may have long-lasting effects on their social and emotional behavior.¹⁵ Other studies showed that children who were moved from an institution into family-based environment demonstrated signs of improvement in their intellectual functioning, attachment patterns, reduced signs of emotional withdrawal, and reduced prevalence of mental health conditions.¹⁶

At time of writing, Serbia did not have a comprehensive plan on the deinstitutionalization of children and adults with disabilities. In 2014, the Protector of Citizens – the Ombudsman of the Republic of Serbia – produced a Roadmap to Deinstitutionalization in Serbia,¹⁷ which was presented to the National Assembly. However, according to the

¹² Republic Institute for Social Protection, Children in Social Welfare for 2014 [In Serbian: Deca u sistemu socijalne zaštite 2014.] Belgrade, July 2015. p.39

¹³ Human Rights Watch interview with Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, November 17, 2015.

¹⁴ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

¹⁵ Mulheir Georgette, Deinstitutionalisation: a human rights priority for children with disabilities, September 2012, http://www.equalrightstrust.org/ertdocumentbank/err9_mulheir.pdf (accessed April 30, 2016); Browne Kevin, “The risk of harm to young children in institutional care,” 2009, www.crin.org/en/docs/The_Risk_of_Harm.pdf (accessed April 30, 2016).

¹⁶ Johnson R, Browne K, Hamilton-Giachritsis C., “Young children in institutional care at risk of harm,” https://www.crin.org/en/docs/The_Risk_of_Harm.pdf; Nelson C, et al., “Cognitive recovery in socially deprived young children: the Bucharest early intervention project.” http://www.bucharestearlyinterventionproject.org/Nelson_et_al__combined__2007_.pdf (accessed May 17, 2016); Bos, K. et al., “Psychiatric outcomes in young children with a history of institutionalization,” 2011, http://www.bucharestearlyinterventionproject.org/Bos_et_al__2010_.pdf (accessed May 17, 2016).

¹⁷ The Protector of Citizens, Roadmap to Deinstitutionalization in the Republic of Serbia [In Serbian: Mapa puta deinistucionalizaciji u Republici Srbiji] (Available in Serbian at): <http://www.ombudsman.osobesainvaliditetom.rs/attachments/Mapa%20puta.pdf> (accessed May 9, 2016).

Ombudsman, the government has refused to adopt this document with no clear justification.¹⁸

Small Group Homes

In 2008, the Serbian government in partnership with UNICEF implemented an EU funded Comprehensive Plan for Transformation of Residential Social Care Institutions for Children with the aim of moving children from institutions into the community. However, this plan, which expired in 2013, did not target primarily children with disabilities, but rather children without disabilities or parental care. Some children with disabilities were moved out of only one institution – the Kulina Institution for Persons with Disabilities in Aleksinac, in the south of Serbia – yet even in this case, the majority of children were not moved into family households but rather to another institution or to a small group home (with up to 12 children with disabilities).¹⁹

These five small group homes, established in 2008 where up to 60 children from Kulina have been transferred, were intended to provide family-like environments and temporary accommodation for children with disabilities.²⁰ The Centers for Social Work, the state agencies responsible for social protection, including for protection of children in state custody, were supposed to gradually move the children from the small group homes to live with biological families or in foster care. Currently, the majority of children that had moved to small group homes since 2008 continue to live there.²¹ For example, a caregiver in the small group home in Niš told Human Rights Watch, “Children have been here for four years now. Soon, they will be adults.”²²

Human Rights Watch visited three small group homes in Belgrade, Aleksinac and Niš where 36 children and young people with disabilities live. All three small group homes are

¹⁸ Human Rights Watch interview with Gordana Stevanović, Deputy Ombudsperson for the rights of children; Vladana Jović, Deputy Ombudsperson for the rights of persons with disabilities; and Miloš Janković, Deputy Ombudsperson/National Mechanism for the Prevention of Torture, Serbia, October 16, 2015.

¹⁹ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Dragana Čirić, director, Mental Disability Rights International, Serbia, October 14, 2015.

²⁰ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015.

²¹ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015. Human Rights Watch interview with Gordana Čalija, director of the small group home “Yusa” in Belgrade, Serbia, October 16, 2015. Human Rights Watch interview with Jasna Nikolić, director of the small group home in Aleksinac, Serbia, November 19, 2015.

²² Human Rights Watch interview with a caregiver in the small group home in Niš, Serbia, November 19, 2015.

located in town centers in buildings where children without parental care lived prior to the 2008 Transformation Plan.

In both Aleksinac and Belgrade small group homes there were up to 12 staff members for up to 12 children and the children living there appeared to have more privacy and freedom and to receive individualized attention and support.

For children and young people living in the small group home in Niš, where all children and young people wear diapers except for one 17-year-old, the staff reported that they have only one caregiver and one educator responsible for 11 children and young people with disabilities per shift, making it difficult for staff to provide individualized attention to all children. “They didn’t do it properly. They moved children here, but did not provide enough personnel,” a caregiver explained.²³ The same caregiver told Human Rights Watch that children and young people, all with physical disabilities, live on the upper level of the building and are not able to access elevators on the weekends, leaving the children confined to the building during those days.

Some children and young people who live in the small group homes visited by Human Rights Watch expressed a desire to live with families or in the community on their own. For example, Mihajlo, a 17-year-old boy who uses wheelchair and lives in a small group home in Niš, told Human Rights Watch: “I consider children who live here to be my family, but I would rather live with my dad and my brother [in Belgrade], or in a foster family.”²⁴

Natalia, a 15-year-old girl who lives in the Aleksinac small group home, told Human Rights Watch how she enjoys going to school and playing with other kids from the small group home, but that she would rather live with her family. She also explained that her family, who lives in Novi Sad, 300 kilometers away, is unable to visit her because of the distance and because they do not have the financial resources for travel costs. “Let me tell you something. I want to get away from here. When I am 18, I am going to leave this place and live in an apartment,” Natalia said.²⁵

²³ Human Rights Watch interview with a caregiver (name withheld), small group home in Niš, Serbia, November 19, 2015.

²⁴ Human Rights Watch interview with Mihajlo (pseudonym), small group home [date and name of the small group home withheld].

²⁵ Human Rights Watch interview with Natalia (pseudonym), Serbia, November 19, 2015.

Under the transformation plan, children were placed in small group homes according to their type of disability. For example, all children and young people who live in the Aleksinac small group home have intellectual disabilities, while children who live in the small group home in Niš had development or intellectual disabilities but also used wheelchairs or couldn't walk. A representative from the government explained that creating homogenous groups among children was part of the process of moving children from Kulina Institution to small group homes. They developed children's "functional plans" and according to these plans they were moved to one of five small group homes or to Zvečanska Center for Protection of Infants, Children, and Youth in Belgrade. The representative from the Ministry who was present during Human Rights Watch's visits to institutions and small group homes explained how some 50 children with "moderate forms of disability," most of whom have parents in rural areas, were moved first: "Children with better potential ended up in small group homes and children with extreme, severe conditions were moved to Zvečanska [institution in Belgrade where 150 children with disabilities currently live]."²⁶

Grouping children according to their disability in small group homes that are supposed to be designed to respond to their particular disabilities is not only a form of segregation of children on the basis of disability but may lead to severe developmental consequences for a child's sense of socialization. For example, Mihajlo told Human Rights Watch how he misses talking with friends because the majority of children in his small group home cannot speak: "There are only three of us who can talk."²⁷

The practice of moving children with high support needs to Zvečanska Center for Protection of Infants, Children, and Youth instead of to a family-based environment is discriminatory against children with multiple disabilities. This practice could also lead to significant numbers of children with high support needs spending the rest of their lives in institutions. As of December 2015, there was still one child with a disability and 85 young people with disabilities between 18 and 26 years old living in Kulina Institution.²⁸

²⁶ Human Rights Watch interview with a representative from the Ministry of Social Policy [name withheld at the request], Serbia, November 19, 2015.

²⁷ Human Rights Watch interview with Mihajlo (pseudonym), small group home [date and name of the small group home withheld].

²⁸ Human Rights Watch interview with Mirjana Ognjanović, Republic Institute for Social Protection, Serbia, November 20, 2015.

Family Outreach Service

Bojana [family outreach worker] means a lot to me. I was all burned out before she came. I considered sending Mateo [12-year-old son with psychosocial disability] to an institution. Then, we got Bojana to help us. She is simply there to direct me, to help me look beyond, to provide me with information, to advise me on what to do.

-Jovana, a single mother of a 12-year-old boy with psychosocial disability²⁹

The Family Outreach Service, developed by UNICEF in cooperation with the Ministry of Employment, Labour, Veteran and Social Policy and financed by the Novak Djokovic Foundation, provides support to families where there is a risk of separation of children from their families, including families for children with disabilities. There are eight full-time and eight part-time family outreach workers, supported by expert teams working in institutions, some of whom work with children with disabilities and their families.

Family outreach workers visit families in their community and, depending on the needs of the child and the family, provide relevant practical support and assistance. This can include counseling, advocating for the rights of the child and the family with different agencies, assisting with administrative documentation necessary for families to receive financial support, obtaining health care, and enrolling children in kindergartens, day care centers, and schools.

This initiative is being implemented in four children's homes that are developing community based services: in the Zvečanska Center for Protection of Infants, Children, and Youth in Belgrade, Duško Radović home in Niš, Kneginja Ljubica Developmental Centre in Kragujevac and in SOS Children's Village in Novi Sad.

Families are referred to the service by local Centers for Social Work, the state agency for social welfare, who ensure that the service is available to those who need it most. As of January 2016, 464 families and 1,160 children used this service, of which 79 were families with children with disabilities.³⁰

²⁹ Human Rights Watch interview with Jovana [pseudonym], Serbia, November 17, 2015.

³⁰ Human Rights Watch e-mail communication with UNICEF representative to Serbia, March 9, 2016.

Selma Čatović, a family outreach worker, explained the main principle of the service: “Our mission is to work with the family, not for them, to empower them, not take care of them.”³¹ Lidiya Bukvić, a family outreach worker providing support to children with disabilities and their families told Human Rights Watch that community-based counseling services are much needed: “I spend a lot of time working with families to accept their child’s disability. To look beyond the diagnosis. To see the child in all of her characteristics.”³²

Bojana Brkić, another outreach worker, told Human Rights Watch that children with disabilities and their families face particular difficulties in accessing health care and enrolling in mainstream schools in their communities: “We put a lot of effort and time on working with schools to include children with disabilities in the education system.”³³

Illusion of Decline; Increase in Admissions

The number of children being placed in institutions has decreased. But, the number of children with disabilities in institutions has not changed.

—A family outreach worker, November 2015

According to the Republic Institute for Social Protection, a state agency mandated to conduct research on the social welfare system in Serbia, as of December 2014, 10,896 people with disabilities lived in institutions³⁴ –most of them having entered the institution as children.³⁵ Of this total, 657 were children and 623 young people with disabilities.³⁶

³¹ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidiya Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

³² Ibid.

³³ Human Rights Watch interview with Bojana Brkić, family outreach worker, Serbia, November 17, 2015.

³⁴ Republic Institute for Social Protection, Adults in the system of social protection [In Serbian: Odrasli u sistemu socijalne zaštite], July 2015, p.37, (Available in Serbian at): <http://www.zavodsz.gov.rs/PDF/izvestaj2015/PUNOLETNI%20KORISNICI%20U%20SISTEMU%20SOCIJALNE%20ZASTITE.pdf> (accessed January 13, 2016).

³⁵ Zoran Arbutin, director of Veternik Institution for children and adults with disabilities, October 20, 2015.

³⁶ Republic Institute for Social Protection, Adults in the system of social protection [In Serbian: Odrasli u sistemu socijalne zaštite], July 2015, p.37.

In its 2012 submission to the UN Committee on the Rights of Persons with Disabilities, the Serbian government asserts a slight decline in the number of children with disabilities in institutions.³⁷

363. The table below shows the number of children with disabilities placed at the social protection institutions, including presentation of fluctuations within the last 5 years.⁶⁸

<i>Year</i>	<i>Up to 18 Years</i>	<i>from 18 to 26</i>	<i>Total</i>
2006	840	741	1 581
2007	757	740	1 497
2008	683	716	1 399
2009	611	683	1 294
2010	530	671	1 201

Source: Committee on the Rights of Persons with Disabilities, *Consideration of reports submitted by States parties under article 35 of the Convention. Initial reports of States parties due in 2011. Serbia*. CRPD/C/SRB/1, September 29, 2014, p.59, para.363.³⁸

Based on interviews with local activists and directors of three institutions, however, Human Rights Watch learned that the decrease in the number of children in institutions is at least in part a result of children reaching adulthood and therefore no longer being counted as children, not only as a result of them leaving the institution.³⁹

Human Rights Watch found that when children with disabilities turn 18 years old, they are either placed under “extended parental rights”⁴⁰ and continue to live in orphanages, or are placed in state institutions for adults. As a result, many children remain in institutional care for the rest of their lives.

³⁷ Committee on the Rights of Persons with Disabilities, *Consideration of reports submitted by States parties under art. 35 of the Convention. Initial reports of States parties due in 2011. Serbia*. CRPD/C/SRB/1, September 29, 2014, p.59, para.363.

³⁸ Ibid.

³⁹ Human Rights Watch interview with Dragana Čirić, director, Mental Disability Rights International, Serbia, October 14, 2015; Human Rights Watch interview with Zoran Arbutin, director, Veternik Institution for children and adults with disabilities, Serbia, October 20, 2015; Human Rights Watch interview with Ana Tomašević, director, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

⁴⁰ According to the Serbian Family Law, parental rights can be extended after a person with disabilities reaches the age of 18 in which case the person that has been put under extended parental rights is legally considered a child. See: Family Law, Official Gazette of the Republic of Serbia, No. 18/2005, 72/2011, 6/2015, art. 85, (Available in Serbian at): http://www.paragraf.rs/propisi/porodicni_zakon.html, (accessed January 13, 2015).

For example, in Veternik Institution for children and adults with disabilities, at the time of Human Rights Watch's October 2015 visit, the director reported 59 children living there. The director then explained that by the end of 2015, there would be 50 children in the institution because 9 of them would have turned 18.⁴¹ However, these 9 individuals will continue to live within the same institution as adults.

The director of the Kolevka Home for children with disabilities, explained: "When they turn 18, they go to Veternik, Stamnica, or some other institution for adults."⁴²

The director of the Stamnica Home for children and adults with disabilities told Human Rights Watch, "We have 22 children as of today. Two girls will turn 18 by the end of the year."⁴³ They will continue to live within the same institution, but be counted as adults.

The Serbian government has been slow to transition children and adults with disabilities out of institutions and into the community. The Serbian Republic Institute for Social Protection indicates in its 2014 report that only 68 children with disabilities left orphanages that year, of whom 8 children (aged 6 to 17) were placed in another institution.⁴⁴ It is not clear how many children were transferred to institutions for adults after they reach adulthood. In 2014, 147 children with disabilities were admitted to institutions.⁴⁵ According to local activists and directors of 2 institutions, all institutions in the country have a waiting list.⁴⁶

⁴¹ Human Rights Watch interview with Zoran Arbutin, director, Veternik Institution for children and adults with disabilities, Serbia, October 20, 2015.

⁴² Human Rights Watch interview with Nenad Kozomora, director, Kolevka Home for children with disabilities, Serbia, November 18, 2015.

⁴³ Human Rights Watch interview with Ana Tomašević, director, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

⁴⁴ According to the same report, 24 children have been returned to birth families, 4 children were adopted, and 13 children were placed in foster care. The report further indicates that 3 children left institutions due to "becoming independent," 4 children left the orphanage on their own, and 3 children died. Republic Institute for Social Welfare, Report on the work of institutions for children and youth for 2014 [In Serbian: Izveštaj o radu ustanova za smestaj dece i mlade za 2014.] Belgrade, July 2015, (Available in Serbian at): <http://www.zavodsz.gov.rs/PDF/izvestaj2015/USTANOVE%20ZA%20SMESTAJ%20DECE%20I%20MLADIH.pdf> (accessed May 1, 2016).

⁴⁵ Republic Institute for Social Welfare, Children in the social protection system 2014 [In Serbian: Deca u sistemu socijalne zaštite 2014], Belgrade, July 2015, p.13.

⁴⁶ Human Rights Watch interview with Dragana Čirić, director, Mental Disability Rights International, Serbia, October 14, 2015; Human Rights Watch interview with Zoran Arbutin, director, Veternik Institution for children and adults with disabilities, Serbia, October 20, 2015.

Instead of transitioning persons with disabilities out of institutions and into the community, Human Rights Watch documented an increase in admissions in the last two years in three out of five institutions visited.

For example, in 2014, two adults left the Stamnica Home for Children and Adults with Disabilities, and six persons were admitted, including one child.⁴⁷ As of October 2015, no one had left this institution during the year, while one person was admitted.

In 2015, four children with disabilities were moved from the Sremčica Home for children and adults with disabilities and placed in foster care.⁴⁸ During the same year, four other children were admitted to Sremčica.

In Zvečanska, five children and young persons left the institution in 2015. Out of five, three persons were moved to another institution, including the Kulina Institution for Adults with Disabilities, the only institution from which some children were moved out on the basis of the 2008 Transformation Plan.⁴⁹ At the same time, nine children were admitted to Zvečanska, including five babies in 2015.

More Investments in Institutions Instead of Community Care

The government was in the process of refurbishing three out of five large residential institutions⁵⁰ where children with disabilities live and that were visited by Human Rights Watch in October and November 2015.⁵¹ Some of the renovations were undertaken to improve the living conditions for children and adults living there, for example by building

⁴⁷ Human Rights Watch interview with social worker, [name withheld] Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

⁴⁸ Human Rights Watch interview with social worker [name withheld], Sremčica Home for children and adults with disabilities, Serbia, November 16, 2015.

⁴⁹ Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

⁵⁰ According to the institutions staff, as of October 2015, up to 540 people lived in the Veternik Institution for children and adults with disabilities, including 59 children; 345 in the Stamnica Home for children and adults with disabilities, including 22 children; 292 in the Sremčica Home for children and adults with disabilities, including 49 children; 150 children with disabilities in the Zvečanska Center for Protection of Infants, Children, and Youth; and 167 children with disabilities in Kolevka Home for children with disabilities. Human Rights Watch documented that there was a lot of variation in terms of what the staff in institutions visited said about the numbers of children living there.

⁵¹ These are: Institution for children and adults with disabilities in Veternik, Stamnica Home for children and adults with disabilities, Kolevka Home for children with disabilities.

an elevator in the Kolevka Home for children with disabilities in Subotica to facilitate movement within the institution and to the outside.

However, Human Rights Watch found that two isolation rooms were being refurbished in Veternik Institution for children and adults with disabilities, which, according to the director of the institution, are used to separate children and adults from other residents in cases of contagious diseases or until they “adapt” to the institution.⁵² In March 2014, the Serbian government also opened a newly built institution for children and young people with disabilities in Šabac, contradicting its previously expressed commitment to community-based living and appropriate support services for all children in the 2008 Plan on Transformation of Residential Social Protection Institutions for Children.⁵³ According to Serbia’s response to the List of Issues for its initial report to the Committee on the Rights of Persons with Disabilities, 55 million Serbian dinars (approximately US\$505,000) were allocated from the national budget to social welfare institutions for accommodation of children.⁵⁴ On April 19, 2016, Human Rights Watch sent a letter to the Ministry of Labour, Employment, Veteran and Social Policy requesting information on the purpose for which the 55 million dinars was allocated and information on how much the Serbian government allocated from the national budget to develop community services and support for children with disabilities and their families. At time of writing, Human Rights Watch had not received a response.

On April 4, 2016, the Ministry of Labour, Employment, Veteran and Social Policy opened a new building inside of the Stamnica Home for children and adults with disabilities, with the capacity of 112 people.⁵⁵ According to the press statement, 66 million Serbian dinars

⁵² Human Rights Watch interview with Zoran Arbutin, director, Institution for children and adults with disabilities in Veternik, Serbia, October 20, 2015.

⁵³ Comprehensive Plan for Transformation of Residential Social Care Institutions for Children 2009 – 2013, Ministry of Labour, Employment, Veteran and Social Policy, Belgrade, September 2009.

⁵⁴ Committee on the Rights of Persons with Disabilities, *Replies of Serbia to the list of issues, date received: February 5, 2016*, p.7, para.29. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/026/89/PDF/G1602689.pdf?OpenElement> (accessed March 15, 2016).

⁵⁵ Radio Television of Serbia (RTS), “Vulin otvorio novoizgradjeni objekat za ometene u razvoju” [Vulin opened a newly built building for persons with disabilities], April 4, 2016. (Available in Serbian at): <http://www.rts.rs/page/stories/sr/story/125/Dru%C5%A1tvo/2268858/Vulin+otvorio+novoizgra%C4%91eni+objekat+za+ometene+u+razvoju.html> (accessed May 1, 2016).

(approximately US\$606,000) were allocated from the national budget for the building of this new complex.⁵⁶

Serbia's International and National Legal Obligation to Ensure the Right of a Child to not be Separated from His or Her Family

The Convention on the Rights of the Child (CRC)⁵⁷ and the Convention on the Rights of Persons with Disabilities (CRPD)⁵⁸ oblige Serbia to ensure that children with disabilities are protected and enjoy their rights without discrimination. The treaties require Serbia to consider children with disabilities as members of society with rights on an equal basis as others and to remove barriers that prevent children from full inclusion in society. The Serbian Constitution also protects the right of children to be cared for and raised by their parents.⁵⁹

Serbia is also a member of the Council of Europe (CoE), and the Council's Committee of Ministers has issued recommendations to states on actions that need to be taken to ensure full inclusion of children and young persons with disabilities into society⁶⁰ and on deinstitutionalization and community living of children with disabilities.⁶¹

Under the CRC, a child should not be separated from his or her parents against their will, except when such separation is necessary in the best interests of the child.⁶² The

⁵⁶ Ibid.

⁵⁷ Convention on the Rights of the Child (CRC). New York (NY): United Nations General Assembly; 1989.

⁵⁸ Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, Annex I, U.N. GAOR, 61st Sess., Supp. (No. 49) at 65, U.N. Doc. A/61/49 (2006).

⁵⁹ The Constitution of Republic of Serbia, art. 29,

<http://unpan1.un.org/intradoc/groups/public/documents/UNTC/UNPAN019071.pdf> (accessed May 1, 2016).

⁶⁰ Recommendation CM/Rec (2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities, (*Adopted by the Committee of Ministers on February 3, 2010 at the 1076th meeting of the Ministers' Deputies*) [https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Rec\(2010\)2&Language=lanEnglish&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDBo21&BackColorLogged=F5D383](https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Rec(2010)2&Language=lanEnglish&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDBo21&BackColorLogged=F5D383) (accessed April 18, 2016).

⁶¹ Recommendation CM/Rec(2013)2 of the Committee of Ministers to member States on ensuring full inclusion of children and young persons with disabilities into society (*Adopted by the Committee of Ministers on October 16, 2013 at the 1181st meeting of the Ministers' Deputies*) [https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Rec\(2013\)2&Language=lanEnglish&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDBo21&BackColorLogged=F5D383](https://wcd.coe.int/ViewDoc.jsp?Ref=CM/Rec(2013)2&Language=lanEnglish&Site=COE&BackColorInternet=C3C3C3&BackColorIntranet=EDBo21&BackColorLogged=F5D383) (accessed April 18, 2016).

⁶² CRC, art. 9.

Committee on the Rights of the Child, the UN expert body which monitors implementation of the treaty, reinforced this notion, articulating that children with disabilities “are best cared for and nurtured within their own family environment.”⁶³ The Committee has called on States parties to establish programs to deinstitutionalize children with disabilities, returning them to their biological or extended families or placing them in foster care, and providing children’s families with systematic support to include children in their homes.⁶⁴ Parents and other extended family members should be provided with the necessary and systematic support and training for including their child back into their home environment.”⁶⁵

Similarly, under article 23 of the CRPD, children are not to be separated from their families unless it is believed that doing so is in the best interests of the child. Furthermore, the CRPD states: “In no case shall a child be separated from parents on the basis of a disability of either the child or both of the parents,” and requires States parties, in case the immediate family is unable to care for a child with disabilities, to “undertake every effort to provide alternative care with the wider family, and failing that, within the community in a family setting.”⁶⁶

Article 19 of the CRPD further emphasizes the equal right of all persons with disabilities to live in the community, with choices equal to others, and requires States parties to take effective and appropriate measures to facilitate the full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.⁶⁷

The UN Guidelines for the Alternative Care of Children state that in order to meet the emotional, social, and other needs of each child living without parental care, states should

⁶³ CRC, General Comment No. 9: The rights of children with disabilities. Geneva: United Nations Committee on the Rights of the Child; 2006; General Comment No. 7: Implementing child rights in early childhood. Geneva: United Nations Committee on the Rights of the Child; 2006.

⁶⁴ CRC, General Comment No. 9: The rights of children with disabilities. Geneva: United Nations Committee on the Rights of the Child; 2006; para.49.

⁶⁵ Ibid.

⁶⁶ CRPD, art. 23, para. 5.

⁶⁷ CRPD, art. 19.

take all necessary legislative, policy, and financial measures to provide for adequate alternative care options that grant priority to “family and community based solutions.”⁶⁸

Young children, especially those under three years of age, should receive care in family-based settings, except in emergency cases or to prevent the separation of siblings, when residential care should be for a limited duration and “with planned family reintegration or other appropriate long-term care solution as its outcome.”⁶⁹

The UN Committee on the Rights of Persons with Disabilities in its concluding observations from April 21, 2016, called on Serbia to “strengthen its efforts to deinstitutionalize children, [...] to prevent any new institutionalization of infant under the age of 3, and to ensure a more efficient transition of boys and girls from institutions into families.”⁷⁰

The Committee also asked Serbia to adopt a comprehensive plan on deinstitutionalization, to stop investing in new institutions, and to allocate resources to enable persons with disabilities to live in the community.⁷¹

⁶⁸ UNICEF, “Guidelines for the Alternative Care of Children,” undated, para. 53, http://www.unicef.org/protection/alternative_care_Guidelines-English.pdf (accessed February 29, 2016).

⁶⁹ Ibid. para.22.

⁷⁰ Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.14.

⁷¹ Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.41.

The Path to Institutionalization

According to local child and disability experts and institution staff, the majority of Serbian children with disabilities living in institutions have at least one living parent.⁷² Human Rights Watch documented that there are various reasons why children enter institutions and other forms of state care, such as foster care, instead of living with their families and communities.

A key reason for institutionalization is that parents face pressure from medical personnel to place their children with developmental or intellectual disabilities in institutions. Doctors and nurses in Serbia often fail to provide parents with information about their child's health and about access to appropriate services and support groups, instead encouraging parents to place their child with disability in an institution. Lack of health care and support services, poverty, stigma, discrimination, social exclusion and even neglect are other factors why parents may opt to place children with disabilities in institutions in Serbia.

Undue Pressure on and Lack of Information to Parents

Brankica Janković, Serbian Commissioner for Equality, told Human Rights Watch that medical staff, including doctors, often advise parents to place their child with a disability in institutions.⁷³ Jasmina Čuković, mother of Julija, a 4-year-old girl born with Apert syndrome, a rare genetic condition characterized by premature fusion of certain skull bones and webbing of the hands and feet, told Human Rights Watch how healthcare workers in a state hospital where she gave birth to her child did not provide her with any information about her child's health. She told Human Rights Watch:

⁷² Human Rights Watch interview with Dragana Čirić, director, Mental Disability Rights International, Serbia, October 14, 2015; Human Rights Watch interview with Zoran Arbutin, director, Institution for children and adults with disabilities in Veternik, Serbia, October 20, 2015. Human Rights Watch interview with social worker, [name withheld] Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015; Human Rights Watch interview with Dobrila Grujić, director of the Center for Family Placement and Adoption in Belgrade, Serbia, October 14, 2015.

⁷³ Human Rights Watch Interview with Brankica Janković, Commissioner for Equality of the Republic of Serbia, Serbia, December 2, 2015.

No one came to check on me or talk to me. No one said a word about my child. There I was in the same room with other happy mothers. Pediatricians spoke with them and their children were brought into the room to be breastfed, but it was as if I or my child did not even exist. Some medical nurses would try to comfort me by saying: “You will give birth to another child. Don’t cry.” I don’t know why they thought I would find comfort in those words? It is like they immediately wrote my child off.⁷⁴

Jasmina explained that medical doctors and nurses tried to convince her and her husband to leave Julija in the maternity ward and to have her placed in an institution:

One doctor told us, “It will be a torment for you and you don’t know if you will receive anything back.” Medical nurses would tell us, “This is best for you and for her. It is better for her to be with children that are like her.”⁷⁵

According to Ivana Cerović, a social worker who works in the Zvečanska Center for Protection of Infants, Children, and Youth, children born with serious health problems or disabilities in Serbia are often denied the opportunity to bond with their parents upon birth: “In the maternity wards, the practice is that parents do not make physical contact with infants [with disabilities].”⁷⁶ Cerović explained that such practice significantly hinders the establishment of an emotional connection and affectionate relationship between parents and an infant with disabilities. The social worker also confirmed that professional staff in some hospitals instead may be quick to encourage parents to give up on their child with disability:

Adequate professional advice and therapeutic and emotional support to parents is lacking. No information is provided on possible sources of support and instead, in the majority of cases, doctors provide parents with ready-made advice that it is easier and more practical or convenient for the child and for the parents to place the child in an institution.⁷⁷

⁷⁴ Human Rights Watch interview with Jasmina and Ivica Čuković, Serbia, December 1, 2015.

⁷⁵ Ibid.

⁷⁶ Human Rights Watch e-mail communication with Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, February 17, 2016.

⁷⁷ Ibid.

In 2008, the Ministry of Health, in cooperation with the Ministry of Labor, Employment, Veteran and Social Policy and UNICEF, implemented a project entitled “A Child’s Place is within the Family.” One of the goals of the project was to ensure health care professionals do not advise parents to place their child with a disability in an institution, and instead provide them with information they need on how to care for the child at home.⁷⁸ However, results of a focus group study conducted in 2015 and supported by the EU, UNICEF, and the Ministry of Labor, Employment, Veteran and Social Policy, showed that parents of children with disabilities continue to be traumatized by the way health-care professionals communicate with them, including in informing them that their child has a disability.⁷⁹

Human Rights Watch also documented that the government often does not provide sufficient information to parents and their children about their rights and the services, support, and rehabilitation options available to them, or advice on how to meet the needs of their child with a disability. As Ana, a single mother of a 12-year-old girl with physical and intellectual disabilities told Human Rights Watch, “As a parent you don’t know what you are entitled to, no one informs you about your rights, benefits, support. If you find out something, it is by pure accident.”⁸⁰

Ljubiša Jovanović, a family outreach service coordinator, confirmed the lack of information on available options in Serbia:

Often, parents don’t even have anyone to turn to for information. In the majority of cases, their only contact is with healthcare workers whose attitudes often favor institutionalization. Doctors refer parents to send their child to an institution and then there is no one to offer another option.⁸¹

The attitudes of relatives and their support (or lack of) also play an important role in parents’ decision to keep a child with a disability. “From our experiences in working with

⁷⁸ Ministry of Health of Republic of Serbia, Letter from May 9, 2016. Appendix 3

⁷⁹ Human Rights Watch e-mail communication with UNICEF representative to Serbia, April 21, 2016.

⁸⁰ Human Rights Watch interview with Ana [pseudonym], Serbia, November 28, 2016.

⁸¹ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

parents of children with disabilities, often the decision on placement of a child in an institution is linked to feelings of shame and stigma,” Ivana Cerović, a social worker at Zvečanska Center for Protection of Infants, Children, and Youth explained further.⁸²

According to one study in the United States for which parents of children with disabilities were surveyed, the quality of the first information parents receive upon the birth of a child with a disability and the attitude of healthcare workers are key factors that impact the hope parents have for the future of their baby.⁸³ In the absence of such support, the study found, parents often distance themselves from a child with a disability, and they remain convinced that it is best for the child in an institution not to bond. Parents believe that the child will receive adequate health monitoring and "expert" support in an institution that they cannot provide at home. The study also found parents often mistakenly believe that taking care of a child with disabilities might impair the development of other children in the family.⁸⁴

Lack of Community-Based Services

Human Rights Watch found that families which had children with disabilities did not have access to adequate community services and support, such as health care, psychosocial support, and financial assistance to support children with disabilities and their biological families across Serbia.⁸⁵ In fact, according to directors of three Serbian institutions where children with disabilities live, poverty and lack of government-supported services for children with disabilities and their families are key reasons for the placement of children in institutions.⁸⁶

⁸² Human Rights Watch e-mail communication with Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, February 17, 2016.

⁸³ Lemecks et al, *Insights from Parents About Caring for a Child with Birth Defects*, International Journal Environ Res Public Health, August 2013, 10 (8), pp. 3465-3482.

⁸⁴ Ibid.

⁸⁵ Human Rights Watch interview with Dragana Čirić, director, Mental Disability Rights International, Serbia, October 14, 2015

⁸⁶ Human Rights Watch interview with Gordana Stevanović, Deputy Ombudsperson for the rights of children; Vladana Jović, Deputy Ombudsperson for the rights of persons with disabilities; and Miloš Janković, Deputy Ombudsperson/National Mechanism for the Prevention of Torture, Serbia, October 16, 2015.

Lack of Community-Based Health-Care

One of the key reasons for placement of children with developmental disabilities in institutions is the lack of community-based health care. According to the information presented by the Serbian government during the review of Serbia by the UN Committee on the Rights of Persons with Disabilities in Geneva, on April 6, 2016, the prevalent reason for placement of children in institutions is “the inability of parents to meet the health needs of the child in the community where they live.”⁸⁷ The government said that 70.5 percent of children placed in institutions are placed because of this reason.

Jasmina and Ivica Čuković, parents of Julija, the 4-year-old girl with Apert syndrome, told Human Rights Watch that the inability to access the necessary and timely health services in their home town, Kragujevac, played an important role in their decision to place their daughter in an institution:

The only two children’s hospitals that could provide her with adequate health care are based in Belgrade, which is 120 kilometers away from where we live. So, we thought the best solution was to have her stay in Belgrade where she can easily access adequate health care whenever she needed it.

They added: “Julija’s teeth are growing very slowly and difficultly and we are wondering what we can do about it. But when we go to a regular dentist, he knows nothing about it.”⁸⁸

Scarce Support Services

The Serbian government finances foster care and institutions for children and adults from the national budget, while municipalities have the responsibility to develop and finance community-based support services for families.⁸⁹ This results in a large number of children who live in poorer municipalities, or municipalities which have not committed to

⁸⁷ Human Rights Watch meeting with the Serbian delegation to the UN Committee on the Rights of Persons with Disabilities, Geneva, Switzerland, April 6, 2016.

⁸⁸ Human Rights Watch interview with Jasmina and Ivica Čuković, Serbia, December 1, 2015.

⁸⁹ The Government is composed of the prime minister and cabinet ministers. The Government is responsible for proposing legislation and a budget, executing the laws, and guiding the foreign and internal policies. Local governments in Serbia - municipalities, serve as basic units for services and tax collection.

developing these services, without access to any services.⁹⁰ According to local experts and UNICEF, most municipalities lack sufficient funds or commitment to establish quality community services and strengthen existing ones.⁹¹

For example in 2014, using EU IPA funds (Instrument for Pre-Accession funds), the small group home in Aleksinac had set up a respite service that would give families time off from their caregiver responsibilities and allow their children to socialize with others outside the family unit.⁹² However, as IPA funds are limited and the local community decided not to fund it, the respite service is currently not provided.⁹³

Ana, a single mother of a 12-year-old girl with physical and intellectual disabilities who currently lives five days a week in an institution and spends weekends at home, said that the existence of community-based respite services where her daughter could spend some of her time would allow her as a single and full-time employed mother to raise her daughter at home. According to a representative from the Ministry of Labour, Employment and Social Policy, the Serbian government is committed to develop respite services for children with disabilities and their families.⁹⁴ However, local municipalities have the responsibility to develop and fund these services.

The absence of day care facilities and inclusive schools also contribute to parents feeling they have no choice but to send their child to an institution. Ana also told Human Rights Watch about her struggle to find a day care center where her daughter could spend time while she works:

Not one single day care center wanted to accept her. They explained they found her too hyperactive. I've spent a year and half begging for an

⁹⁰ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Saša Stefanović, director, Network of Organizations for Children in Serbia, phone interview, October 19, 2015.

⁹¹ Human Rights Watch interview with Saša Stefanović, director, Network of Organizations for Children in Serbia, phone interview, October 19, 2015; Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

⁹² Human Rights Watch interview with Jasna Nikolić, director of the small group home in Aleksinac, Serbia, November 19, 2015.

⁹³ Ibid.

⁹⁴ Human Rights Watch interview with a representative from the Ministry of Social Policy [name withheld at the request], Serbia, November 19, 2015.

alternative where my daughter could spend her time while I was at work and I did not succeed. Three years ago, with no other option available, I placed her in an institution.⁹⁵

Ana told Human Rights Watch that she has to cover the cost of her daughter's accommodations, amounting to 39,000 dinars per month (approximately US\$356). Under the Law on Social Welfare, in order for the state to cover these expenses, Ana explained she would have to give up her parental rights. "I could go and ask to be deprived of parental rights in which case the State would relieve me of all obligations and the State would pay for her accommodations. As long as I keep my parental rights, I must pay for her accommodations."⁹⁶

Human Rights Watch research found that where community services do exist, they are limited in scope. For example, the family outreach service, developed by UNICEF in 2013, which provides support to families where there is a risk of the separation of children from their families, is being implemented in only four major cities in Serbia, with limited financial resources and no long-term sustainability.⁹⁷ The family outreach service is currently financed by a private foundation, not by the Serbian government.

Human Rights Watch found that continuity of services is also a real problem. "Some good services existed for some time and then ended," a family outreach worker explained.⁹⁸ For example, Maja, mother of a six-year-old with cerebral palsy, told Human Rights Watch how the therapeutic sessions offered at the Day Center in Aleksinac that her daughter benefitted from were canceled for a few months in 2015 due to the lack of funding.⁹⁹

Brankica Janković, the Commissioner for Equality, and Ljubiša Jovanović, coordinator of the family outreach service at Zvečanska Center for Protection of Infants, Children, and Youth told Human Rights Watch that the system of early and continuous support for

⁹⁵ Human Rights Watch Interview with Ana (pseudonym), Serbia, November 28, 2015.

⁹⁶ Ibid.

⁹⁷ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

⁹⁸ Human Rights Watch interview with Bojana Brkić, family outreach worker, Serbia, November 17, 2015.

⁹⁹ Human Rights Watch interview with Maja (last name withheld), Serbia, November 19, 2015.

children and their families is underdeveloped in the country.¹⁰⁰ “The importance of early and continuous support for children is not recognized. Early support would significantly reduce the need for support in the future,”¹⁰¹ the Commissioner explained.

Jasmina Čuković, Julija’s mother, said:

One shouldn’t be released from the maternity ward and told to go home and live one’s life alone. [There should be] someone to take care of you, truly take care of you. I think that this would be an additional form of support for parents that is truly necessary.

According to an analysis by the Network of Organizations for Children of Serbia in 2013, family support prior to separating a child from its family was provided in only 15 percent of the cases.¹⁰²

Some parents of children with disabilities as well as foster carers also told Human Rights Watch that they need counseling.¹⁰³ A family outreach worker confirmed how the majority of families she supports need psychological support.¹⁰⁴

Under the Convention on the Rights of Persons with Disabilities, Serbia is obliged to ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, States parties should provide early and comprehensive information, services and support to children with disabilities and their families.¹⁰⁵

¹⁰⁰ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

¹⁰¹ Human Rights Watch interview with Brankica Janković, Commissioner for Equality of Republic of Serbia, Serbia, December 2, 2015.

¹⁰² Human Rights Watch interview with Saša Stefanović, director, Network of Organizations for Children in Serbia, phone interview, October 19, 2015.

¹⁰³ Human Rights Watch interview with Jasmina and Ivica Čuković, Serbia, December 1, 2015. Human Rights Watch interview with Nebojša and Suzana Terzić, Serbia, November 19, 2015. Human Rights Watch interview with Nevena (pseudonym), foster parent, Serbia, November 30, 2015.

¹⁰⁴ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

¹⁰⁵ CRPD, art. 23, para. 5.

Lack of Inclusive Education

National law protects the right to free and compulsory primary education for all children and the right to free secondary education for all persons.¹⁰⁶ The law guarantees the right to support and an individualized approach if needed. A number of Serbian laws explicitly prohibit discrimination on the basis of disability including the law on education.¹⁰⁷

However, Human Rights Watch research found that the majority of children and young people with disabilities in Serbia are either segregated in separate schools for children with disabilities or are not given opportunities for education at all. According to the Ministry of Education it is estimated that approximately up to 50 percent of children with disabilities in Serbia are not enrolled in schools.¹⁰⁸ In the 2015/2016 school year, 6,217 children were enrolled in special schools, according to the Ministry of Education.¹⁰⁹ In addition, there were 250 “special classrooms” “within mainstream schools for 1,474 children with disabilities.”¹¹⁰

The right to live in the community for children with disabilities, as guaranteed by the Convention on the Rights of Persons with Disabilities, also involves being able to attend school, access healthcare in the community, and enjoy play and leisure activities on an equal basis with other children.¹¹¹

Inclusive education focuses on ensuring the whole school environment is designed to foster inclusion, not segregation.¹¹² This includes the right to access quality learning, which focuses and builds children’s abilities, and for children to be provided with the level of

¹⁰⁶ Law on Fundamentals of the Education System, Official Gazette of the Republic of Serbia, No. 72/2009, 52/2011, 55/2013, 35/2015, and 68/2015, available at (In Serbian):

http://www.paragraf.rs/propisi/zakon_o_osnovama_sistema_obrazovanja_i_vaspitanja.html (accessed February 3, 2016).

¹⁰⁷ Constitution of the Republic of Serbia, art. 21; The Law on Prevention of Discrimination against Persons with Disabilities (2006), art. 3; Law on Amendments to the Law on Prohibition of Discrimination, art. 26; Law on Fundamentals of the Education System, art. 44.

¹⁰⁸ Human Rights Watch interview with Gordana Četković, Head of the Group for Social Inclusion, Ljiljana Simić, Associate for Inclusive Education, Snežana Jaković, Advisor for Social Inclusion, Ministry of Education, Serbia, December 4, 2015.

¹⁰⁹ Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1.

¹¹⁰ Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1

¹¹¹ See Camilla Parker and Luke Clements, *The European Union Structural Funds and the Right to Community Living*, http://www.equalrightstrust.org/ertdocumentbank/err9_parker_clements.pdf (accessed July 10, 2014).

¹¹² CRPD, General Comment No. 2 (2014), art. 9: Accessibility, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/033/13/PDF/G1403313.pdf?OpenElement> (accessed May 19, 2016), para. 39;

support and effective individualized measures required to “facilitate their effective education.”¹¹³

In Serbia, most mainstream kindergartens and schools continue to be inaccessible for children with disabilities, particularly children with developmental or intellectual disabilities. Many schools also refuse to admit children with disabilities on the basis that they do not have the resources or skills to educate them.¹¹⁴

Lidija Bukvić, a family outreach worker, told Human Rights Watch that in her experience, local primary schools often refuse to enroll children with disabilities despite being legally obliged to do. She said, “I worked for a month on enrolling a child in her local school. When the school finally enrolled the child, it was a struggle to keep her in school. The teacher would continuously complain to me saying, ‘I don’t know how to deal with her.’”¹¹⁵

In an April 28, 2015 letter to Human Rights Watch, the Ministry of Education acknowledged “the uneven quality of support” provided to children with disabilities in mainstream schools, but rejected reports that children with disabilities are denied enrollment: “the Ministry does not have information about whether any school have refused to enroll a child with developmental disorders or disabilities, or any other child from vulnerable groups.”¹¹⁶ The Ministry said that there have been rare instances where there was resistance to enrollment, but that there are mechanisms in place on how to address such situations.¹¹⁷

Human Rights Watch found that children with disabilities who live in the community spend the majority of their time in day care centers (so-called “living rooms”) or at home. In principle, the development of day care centers is a positive step in providing support and accommodation during the working hours of parents, and as a support service to schools. For example, Zvečanska Center for Protection of Infants, Children, and Youth established such a day care center with the primary purpose of facilitating the inclusion of children

¹¹³ CRPD 24 (2) (d), (e).

¹¹⁴ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

¹¹⁵ Ibid.

¹¹⁶ Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1.

¹¹⁷ Ibid.

with disabilities who already live with their families in kindergartens or schools and to facilitate family reunification for children who live in the institution. For example, according to Ivana Cerović, the social worker at Zvečanska Center for Protection of Infants, Children, and Youth, when they started the day care center in 2014 the majority of children who came to the center were not enrolled in schools.¹¹⁸ The program was able to help 60 percent of them enroll in kindergartens or schools.¹¹⁹ Day care centers prepare an individual plan for each child, working with the child, the family, and the wider community (kindergartens or schools) on inclusion in the society and enrollment in special and mainstream schools.

Day care centers, however, should not become a substitute for enrollment in school.¹²⁰ According to local experts and UNICEF, most day care centers in Serbia are places where children and adults with disabilities who do not go to school or hold a job spend their time.¹²¹ These centers are only for children and adults with disabilities, further segregating and isolating them.

Children who live in small group homes in Belgrade and Aleksinac are included in the education system. However, even in this case, all children go to special schools exclusively for children with disabilities rather than in mainstream schools for all children. Of the children and young people who live in the small group home in Niš, four children go to special schools and seven children receive education inside the home.¹²²

Of the 48 children and families interviewed for this report, Human Rights Watch met only two children, a 12-year-old girl with an intellectual disability and a 12-year-old boy with psychosocial disabilities, who live with their birth and foster families and attend mainstream schools.

¹¹⁸ Human Rights Watch e-mail communication with Ivana Cerović, social worker in Zvečanska Center for Protection of Infants, Children, and Youth, February 17, 2016.

¹¹⁹ Ibid.

¹²⁰ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Saša Stefanović, director, Network of Organizations for Children in Serbia, phone interview, October 19, 2015; Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

¹²¹ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Dragana Ćirić, director, Mental Disability Rights International, Serbia, October 14, 2015.

¹²² Human Rights Watch interview with a caregiver in the small group home in Niš, Serbia, November 19, 2015.

According to Serbian law, parents or legal guardians of children with disabilities make the decision on whether a child will attend mainstream or special school.¹²³

Four birth and foster parents told Human Rights Watch they decided to enroll their child with a disability in a special school out of fear that the child will be neglected and will not receive quality education in a mainstream school. One of such parents is Maja, a mother of a six-year-old child with cerebral palsy who is also a teacher in a mainstream school, who told Human Rights Watch: “There are 30 children in my classroom. It is literally impossible to have an individual approach with every child. I would rather have my daughter get the attention and support she needs to thrive in special school than to languish in a general school.”¹²⁴

Nevena, foster parent of Miloš, who is deaf, told Human Rights Watch how Miloš also attends a special school for children with hearing difficulties. She believes it is her only choice, saying, “Inclusive schools exist only on paper in Serbia.”¹²⁵

In the letter to Human Rights Watch, the Ministry of Education said it does not have information on the number of children with disabilities who are enrolled in schools in their communities. The ministry recognized the need to improve data collection, and provided information on concrete steps taken to improve data collection on children with disabilities and their right to access education.¹²⁶

As a positive step, the Serbian government has developed a service of ‘personal escorts’ for children with disabilities who assist the children with transportation between school and home, and provide assistance in their daily activities at school. The Ministry of Education told Human Rights Watch that according to its data 709 children with

¹²³ Law on Primary Education, Official Gazette of the Republic of Serbia, No. 55/2013, art. 8. (Available at in Serbian): http://www.paragraf.rs/propisi/zakon_o_osnovnom_obrazovanju_i_vaspitanju.html [accessed April 20, 2016].

¹²⁴ Human Rights Watch interview with Maja (last name withheld), Serbia, November 19, 2015.

¹²⁵ Human Rights Watch interview with Nevena (pseudonym), foster parent, Serbia, November 30, 2015.

¹²⁶ According to the letter, the steps include: 1. Amendments to the Law on Fundamentals of Education, which would introduce the system of unified education number for every child. The unified education number would enable a more efficient data collection and evaluation of children in need of support in education; 2. The Ministry of Education is involved in the working group established by the Ministry of Health which working group is responsible to establish a registry for children with disabilities; 3. The Ministry of Education has initiated development of a database software for education. Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1.

disabilities in Serbia use this service¹²⁷ but also recognized the need to scale it up: “On an almost daily basis, parents approach the competent authorities with requests for this type of support which some local self-administration units unfortunately still cannot fund to a sufficient extent.”¹²⁸

The Ministry of Education in cooperation with UNICEF has also developed a hotline service for parents of children with disabilities.¹²⁹ The hotline service is implemented by the nongovernmental organization VelikiMali and provides parents with an opportunity to access information on services available for children with disabilities. According to the Ministry of Education, parents usually have questions on how to access personal escorts and access to education such as the process of enrollment in mainstream and special schools and how to move children from special to mainstream schools.¹³⁰

Poverty and the Broken Foster Care System

She has made our family complete.

-Suzana, a foster parent of Marina, a four-year-old girl with developmental disabilities¹³¹

Serbia is developing and promoting foster care through Centers for Family Placement as an alternative to institutionalization. As of November 2015, 808 children with disabilities lived in foster care. Ongoing work includes broadening foster care services for children with disabilities across Serbia. Each foster family is supported by a foster family associate, who is responsible for supporting and counseling the families as well as supervising foster parents.

Human Rights Watch visited and interviewed three foster families in Belgrade and Nis, each of whom is fostering one child with a disability. Two of the children previously lived in institutions and one child had lived with her birth family. Human Rights Watch also

¹²⁷ Human Rights Watch e-mail communication with the Ministry of Education of Republic of Serbia, May 19, 2016.

¹²⁸ Ministry of Education of Republic of Serbia, Letter to Human Rights Watch, April 28, 2016.

¹²⁹ Ibid.

¹³⁰ Ibid.

¹³¹ Human Rights Watch interview with Nebojša and Suzana Terzić, Serbia, November 19, 2015. Marina is not identified by her real name to protect her privacy.

interviewed one of the children currently placed in foster care and one foster family associate.

Nevena, Miloš's foster parent told Human Rights Watch how she decided to become a foster parent after volunteering in an institution. "Children who live in institutions don't have anyone but their caregivers who are responsible for a large number of children. I wanted to give one child more stability, more love, a family," Nevena said.¹³² Nevena said she met Miloš in the institution where she volunteered when he was just 18-months-old. She told Human Rights Watch, "He was diagnosed with autism, no one knew what to do with him. It took me eight months to get him to smile. It was only when he was two that it turned out Miloš is not autistic, but deaf."¹³³

Suzana, a foster parent to Marina, a four-year old girl with developmental disabilities, told Human Rights Watch how it was impossible to touch the girl when she first came to their home from an institution three years earlier:

Marina was 10-months-old when she came. She was a baby who couldn't sit or hold her head up. If I would touch her little hands or feet, she retracted, like a turtle inside of her shell. For about two or three months we struggled to establish some sort of physical contact. The first time she rested her head on my shoulder was three months after coming to our home. It was the most beautiful thing that happened.¹³⁴

Spomenka Savić, a foster family adviser, who worked previously for 20 years in an institution, said the care and love children receive in foster care is incomparable: "In institutions, it was group work. We couldn't develop love like these parents do," she said.¹³⁵

¹³² Human Rights Watch interview with Nevena (pseudonym), foster parent, Serbia, November 30, 2015.

¹³³ Ibid.

¹³⁴ Human Rights Watch interview with Nebojša and Suzana Terzić, Serbia, November 19, 2015. Marina is not identified by her real name to protect her privacy.

¹³⁵ Human Rights Watch interview with Spomenka Savić, foster family associate, Serbia, November 19, 2015.

However, according to local experts, children with disabilities are more likely to be put in alternative care arrangements than receive support in their birth families.¹³⁶ For example, Selma Čatović, a family outreach worker, told Human Rights Watch:

Children are often removed from their birth families simply because of poverty. What happens then is that [the Center for Social Work] sends a request for foster care or, if unsuccessful, for institutional placement. There are more children in institutions because of financial challenges than because they were abandoned by their parents. And, when it comes to foster care, in the majority of cases, children with disabilities will be declared to be “unsuitable for foster care”¹³⁷

According to family outreach workers and institution staff, a significant proportion of children in Serbian institutions are there because their families are poor and do not have the resources to meet their child’s basic needs.¹³⁸ Parents should never feel that they have no choice but to place their children in care because of poverty. Instead the state should provide parents access to social and economic support in order to safeguard and protect their family and the rights of the child.

According to the Rulebook on Foster Placement, a child who is separated from her or his family will be placed in foster care following the “assessment of the suitability of the child for foster care.”¹³⁹ The assessment includes the circumstances in which a child lives and the individual characteristics and needs of a child.¹⁴⁰ According to a family outreach worker, a child with a disability will often be declared unsuitable for foster care due to the

¹³⁶ Human Rights Watch interview with Saša Stefanović, director, Network of Organizations for Children in Serbia, phone interview, October 19, 2015; Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

¹³⁷ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

¹³⁸ Ibid.

¹³⁹ Rulebook on Foster Placement, Official Gazette of the Republic of Serbia, No. 36/2008, art. 14. http://www.paragraf.rs/propisi/pravilnik_o_hraniteljstvu.html (accessed May 5, 2016).

¹⁴⁰ Ibid. art. 16.

disability.¹⁴¹ Historically there has been insufficient oversight and monitoring to ensure adequate protection of children living in foster families. Human Rights Watch interviewed five young people with disabilities placed in foster care five to six years prior to the Human Rights Watch visits, who reported experiencing physical abuse, including one case of sexual abuse, while in foster care.

Dobрила Grujić, director of the Center for Foster Placement in Belgrade told Human Rights Watch that a foster family adviser is obliged to visit a child in foster care once per month and is obliged to report on the well-being of the child.¹⁴²

Concerning the supervision of foster families, Nevena herself currently a foster parent, said:

We need better monitoring. Less abuse would happen. For example, a foster family adviser is obliged to visit a family once per month and inspect the journal foster parents are obliged to keep. The journal is nothing but a formalistic requirement.¹⁴³

Foster care in Serbia is also currently provided as the main option for relocating children out of institutions. There is insufficient effort to reunite children with disabilities with their birth families and support birth families in raising children with disabilities.¹⁴⁴ For example, Ivica Čuković, Julija's father, explained:

Foster care is an important institution providing care for children who are truly abandoned by their parents, but it shouldn't be a substitute for birth

¹⁴¹ Human Rights Watch interview with Ljubiša Jovanović, coordinator of the family outreach service, Selma Čatović, family outreach worker, Lidija Bukvić, family outreach worker, Ivana Cerović, social worker, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, October 16, 2015.

¹⁴² Human Rights Watch interview with Dobрила Grujić, director of the Center for Foster Care in Belgrade, Serbia, October 14, 2015.

¹⁴³ Human Rights Watch interview with Nevena (pseudonym), foster parent, Serbia, November 31, 2015.

¹⁴⁴ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Dragana Ćirić, director, Mental Disability Rights International, Serbia, October 14, 2015. Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

families who do want to care for their children but need support to do so. The attention should also be directed back to birth families, too.¹⁴⁵

In addition, the Rulebook on Foster Placement obliges the centers for social work to support birth families with the aim of rehabilitating and supporting parents so they can care for their child.¹⁴⁶ However, according to local experts, there is a lack of efforts towards supporting birth families so they can meet their children's needs and be reunited.¹⁴⁷

Human Rights Watch research found that a parent of a child with high support needs who lives in the community often stays at home to care for the child, forfeiting paid employment and placing financial strain on the family. At the same time, a parent in Serbia cannot be recognized as the caregiver of their child with disabilities in the same way as a foster parent, meaning that a parent cannot be compensated for taking care of a child with disability. This also often means that the family has difficulty paying for the necessary therapeutic services, medication, or transport to appointments. The lack of these services and supports can compel some parents to reluctantly place their child in an institution.

¹⁴⁵ Human Rights Watch interview with Jasmina and Ivica Čuković, Serbia, December 1, 2015.

¹⁴⁶ Rulebook on Foster Placement, art. 19.

¹⁴⁷ Human Rights Watch interview with UNICEF representative to Serbia, Serbia, October 15, 2015; Human Rights Watch interview with Dragana Ćirić, director, Mental Disability Rights International, Serbia, October 14, 2015. Human Rights Watch interview with Valentina Zavišić, director, VelikiMali, phone interview, October 23, 2015.

Abuse of Children with Disabilities in Institutions

Based on interviews with children and young people with disabilities, institution staff, and activists, as well as visits to five institutions, Human Rights Watch found that children and young persons with disabilities experience a range of situations in Serbian institutions in which their human rights are violated.

These include segregation and seclusion, neglect, lack of privacy, insufficient safeguards, involuntary and potentially inappropriate medical treatment, lack of education and play, denial of legal capacity upon reaching adulthood, and limited freedom of movement.

Segregation and Seclusion

Many children and young people with disabilities in institutions are confined to cribs or beds all day, seven days a week, in so-called “wards for the most severely disabled,” a term used by institution staff. In both the Stamnica Home for Children and Adults with Disabilities and the Veternik Institution for children and adults with disabilities, children were confined to cribs in the same room and wards as adults. In Stamnica, where 7 children and 57 adults with disabilities live in the “ward for the most severely disabled,” up to 17 people lived together in one room.

In the Kolevka Home for children with disabilities, up to 30 children with developmental and intellectual disabilities, including newborn babies, were confined to cribs in rooms without natural light or fresh air. There were no windows in the rooms, no space for children to play, and apart from the cribs there was no other furniture in the room. Up to 11 children lived together in one room, with one caregiver responsible for all of them. None of these children attends school.

In the same ward, but in a separate room, Human Rights Watch met a seven-year-old Roma boy with intellectual and physical disabilities, who is also HIV positive. Institution staff explained that he does not go to school and is not allowed to eat or play with other children because of the fear that he could infect other children: “We had a girl with him for a while, but then we took her out because we were worried about her safety. We worried

they could scratch each other.”¹⁴⁸ He has been living in this institution since he was one year old.

According to the staff, children and young people who live in the “wards for the most severely disabled” in Kolevka and Stamnica institutions have little to no movement within the institution, time outside, or interaction with the community. A psychologist in Kolevka explained: “These children never go outside because we are on the second floor and they cannot walk.”¹⁴⁹ Institution staff in Stamnica explained that it is difficult for people from the “ward for the most severely disabled” to go outside because only four caregivers are responsible for 64 people who all need assistance with movement.¹⁵⁰

According to the nation’s Ombudsperson, the situation was the same for children and adults who live in the “ward for the severely disabled” in Veternik Institution for children and adults with disabilities in 2014.¹⁵¹ During Human Rights Watch’s visit to the Veternik institution in October 2015, the staff explained that, following recommendations issued by the Ombudsperson,¹⁵² children and young people who lived in the “ward for the severely disabled” were moved from the upper floor to the ground floor in July 2015 to make it easier for caregivers to take them outside.¹⁵³ Human Rights Watch could not verify whether this resulted in children with high support needs indeed spending time outside.

In two institutions visited, Human Rights Watch found that staff put children in isolation rooms. The staff explained that the purpose of isolation is to ensure that children do not carry contagious illnesses into the institution or to help them adapt to the institution.¹⁵⁴ For

¹⁴⁸ Human Rights Watch interview with psychologist, Kolevka Home for children with disabilities, Serbia, November 18, 2015.

¹⁴⁹ Ibid.

¹⁵⁰ Human Rights Watch interview with institution staff, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

¹⁵¹ Human Rights Watch interview with Gordana Stevanović, Deputy Ombudsperson for the rights of children; Vladana Jović, Deputy Ombudsperson for the rights of persons with disabilities; and Miloš Janković, Deputy Ombudsperson/National Mechanism for the Prevention of Torture, Serbia, October 16, 2015.

¹⁵² Protector of Citizens of the Republic of Serbia – National Preventive Mechanism, *Report of Visit to “Veternik” Residential Centre*, March 12, 2014. (Available in Serbian at): http://www.ombudsman.rs/index.php/lang-sr_YU/izvestaji/posebni-izvestaji/4368-2015-10-14-09-13-19 (accessed January 20, 2016).

¹⁵³ Human Rights Watch interview with a medical nurse, Institution for children and adults with disabilities in Veternik, October 20, 2015.

¹⁵⁴ Human Rights Watch interview with institution staff, Veternik Institution for children and adults with disabilities, October 20, 2015.

example, a Human Rights Watch researcher found one child confined to an isolation room in Veternik where, according to the staff, he sleeps, eats, and uses the toilet. The isolation room had a small twin size bed with white sheets, there were no personal belongings, toys, or any other furniture, and the boy was dressed in a white hospital gown. The toilet inside of the room was separated from the sleeping area. There was no space for the boy to play or run around. According to the director of the institution, a medical nurse is present in the room with the child and a child usually stays in an isolation room up to five days.¹⁵⁵

The 2006 UN World Report on Violence Against Children identifies nonphysical forms of violence typically inflicted on children that can be “detrimental to a child’s psychological development and well-being” to include persistent threats, insults, name-calling, ignoring, isolation, rejection, threats, emotional indifference, and belittlement.¹⁵⁶

Neglect

The biggest problem is lack of staff. We have 4 special education therapists, 10 rehabilitation therapists, and 4 work instructors for 300 plus people. One caregiver is responsible for 20 people.

—Specialized educator, Stamnica Home for Children and Adults with Disabilities, October 21, 2015

Lack of individualized attention from caregivers is a significant problem documented in all large institutions Human Rights Watch visited, in many cases leading to neglect. Research has shown that the absence of a one-to-one relationship with a primary caregiver is a major cause of harm to a child’s development and attachment disorders.¹⁵⁷

The lack of individualized attention is likely due in part to the lack of personnel to care for large numbers of children and adults with disabilities. A significant factor contributing to such a low number of staff in Serbian institutions is due to the government’s decision to freeze recruitment in the public sector as of December 2013.

¹⁵⁵ Ibid.

¹⁵⁶ Paulo Sergio Pinheiro, “World Report on Violence Against Children,” UN, 2006, [http://www.unicef.org/lac/full_tex\(3\).pdf](http://www.unicef.org/lac/full_tex(3).pdf)

¹⁵⁷ Inge Bretherton, “The Origins of Attachment Theory: John Bowlby and Mary Ainsworth,” 1992, http://www.psychology.sunysb.edu/attachment/online/inge_origins.pdf (accessed May 4, 2016).

For example, in Stamnica Home for children and adults with disabilities, in the “ward for the most severely disabled,” there were four caregivers and one nurse for 64 children and adults with disabilities. Other than taking care of basic needs such as bathing, diaper changes and feeding, there is little time for individual care or interaction with the children. For example, staff in Kolevka Home for children with disabilities explained that the primary role of the scarce caregivers in the institution is to provide nursing and physical care.¹⁵⁸ The vast majority of children living in this ward are not toilet trained and could not eat by themselves and were instead fed by nasogastric tubes.¹⁵⁹

Human Rights Watch found most babies and children living in Kolevka Home’s “ward for the most severely disabled” lying down on their back, staring at the ceiling or wall, with no stimulation or interaction. In one of the rooms, Human Rights Watch found a 15-year-old boy with untreated hydrocephalus, lying motionless on a bed on his back.

Institution staff recognized the lack of individual time they can provide to children with disabilities. For example, Ana Tomašević, director of Stamnica, told Human Rights Watch, “All of them need affection and attention but they cannot receive it here.”¹⁶⁰ A social worker in Veternik Institution for children and adults with disabilities explained, “We are only two compared to 540 residents. In what way can we devote individualized work?”¹⁶¹

In addition to overall low numbers of staff, in all institutions visited the staff complained about the lack of qualified personnel for much-needed services including, variously, child psychiatrists, psychologists, speech therapists, and physical therapists.

Human Rights Watch found that many children and young people with disabilities in Veternik, Stamnica, and Kolevka institutions wear diapers and are not toilet trained. This is particularly the case with children and adults in the “wards for the most severely disabled,” but Human Rights Watch observed children in other wards wearing diapers as

¹⁵⁸ Human Rights Watch interview with institution staff [name withheld], Kolevka Home for children with disabilities, Serbia, November 18, 2015.

¹⁵⁹ Institution staff explained that tubes are used because of swallowing difficulties. Human Rights Watch interview with institution staff [name withheld], Kolevka Home for children with disabilities, Serbia, November 18, 2015.

¹⁶⁰ Human Rights Watch interview with Ana Tomašević, director, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

¹⁶¹ Human Rights Watch interview with social workers, Veternik Institution for children and adults with disabilities, Serbia, October 20, 2016.

well. Diapers are in short supply with only two diapers per person/child per day in all institutions visited.

Toilet training any child requires patience and individualized support and can be a challenging and time consuming task for overwhelmed caregivers in Serbian institutions. However, just as with learning to feed and dress oneself, becoming toilet trained is an important step in personal independence for children.

Lack of Privacy for Personal Care

Human Rights Watch research revealed that in the complex of the Stamnica institution where children and young people with disabilities live there were no doors or means of privacy separating the toilets in the bathroom. There were also no showers and the institution staff and the children told Human Rights Watch that they use water hoses to bath the children. Two institution staff explained that the reason why there are no showers is because residents broke them.¹⁶²

In two other large institutions visited, there were no doors or curtains separating the showers in the bathing facility.

In the Veternik Institution for children and adults with disabilities, a Human Rights Watch researcher observed that in addition to no separation in the bathing and toilet facility, there were no doors on several rooms where children with disabilities live, giving residents very limited privacy. Two brothers in their early twenties who have lived in Veternik since they were children told Human Rights Watch that the doors were taken down a long time ago, “We would love to have doors to our room.”¹⁶³

In Stamnica, several beds—sometimes up to three—were pushed together, and some beds had thin mattresses even though residents who lived in this ward could not walk and spent the majority of their days lying down. Institution staff stated that they would push three

¹⁶² Human Rights Watch interview with specialized educator and specialized pedagogist, Sremčica Home for children and adults with disabilities, Serbia, October 21, 2015.

¹⁶³ Human Rights Watch interview with two brothers in their early twenties, (names and other details withheld).

beds together, “...so that the person in the middle does not fall down out of the bed.”¹⁶⁴ This arrangement grants the person in the middle no privacy or personal space.

Insufficient Safeguards Against Abusive Use of Restraints and Physical and Psychological Violence

Human Rights Watch did not document any evidence of regular or widespread physical or psychological violence by staff against children with disabilities in institutions, nor evidence of the resorting to abusive use of physical restraints on children. However, interviewees did report incidents of such abuses that had taken place a number of years before Human Rights Watch’s visit. Human Rights Watch notes that in 2012, the Serbian government adopted the “Rulebook on Prohibited Practices of the Employees in Social Protection”,¹⁶⁵ which specifically prohibits all forms of violence by employees in social welfare homes against residents, including physical, sexual, and emotional abuse. The rules further prohibit exploitation of residents, abuse of trust or power that institution staff enjoy in relation to residents, and any other practices that distort the health, dignity, and development of residents. This document stresses the need for the protection of children. Declining number of incidents may be as a result of the enforcement of the rulebook.

However Human Rights Watch is concerned that given the conditions observed in several institutions and the absence of effective safeguards – including no confidential complaint mechanism for people with disabilities in institutions, and a lack of independent and periodic monitoring of institutions - creates a risk that such abuses could still occur with impunity despite the rulebook.

Interviewees told Human Rights Watch about seven instances of various forms of psychological or physical violence by staff that are alleged to have occurred between three and five years prior to the visit of Human Rights Watch, as well as two recent alleged cases. Likewise, children and young people with disabilities also described the use of physical restraints by institution staff, which could often be for a whole day, that mainly took place

¹⁶⁴ Human Rights Watch interview with institution staff, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

¹⁶⁵ Rulebook on Prohibited Practices of the Employees in Social Protection, Official Gazette NO. 8/2012, <http://pzs.gov.rs/multimedia/dodaci/pravilnik%20o%20zabranjenim%20postupanjima.pdf> (accessed May 4, 2016).

a year or more prior to Human Rights Watch’s visits to the institutions. For example, Nenad, a 20-year-old man in Veternik institution, reported being restrained on different occasions three or four years prior to Human Rights Watch’s visit: “They tied my feet and hands to a bed. It was awful. Made me extremely sad. I was tied like that for an entire day.”¹⁶⁶

Two women told Human Rights Watch they witnessed staff using physical restraints on other residents. “There was this one resident “Zlatko” who would often be forced on to the bed and then they would tie him. He would stay like that for two or three hours,” one of the two women told Human Rights Watch.¹⁶⁷

One medical doctor in Stamnica institution told Human Rights Watch that the policy in that institution is that physical restraints can’t be used for longer than two hours at a time.¹⁶⁸ Serbian law neither regulates nor prohibits the use of physical restraints in social welfare homes and according to a representative from the Ministry of Labour, Employment, Veteran and Social Policy and institution staff, every institution has its own “rulebook” on the use of physical and chemical restraints. Human Rights Watch requested to see the relevant rulebooks during each visit to the various institutions, but was never shown any. Human Rights Watch also observed that some institution staff used derogatory language when speaking to children and young people with disabilities. For example, some staff who spoke to Human Rights Watch stated that the children have no potential to learn or go to school. Three staff remarked that “no one wants them” in the presence of the children.

Right to be Free from Violence and Neglect

As a party to the Convention against Torture, the CRC, CRPD, and the European Convention on Human Rights (ECHR), Serbia is obligated to protect children with disabilities from all

¹⁶⁶ Human Rights Watch interview with Nenad (pseudonym). Nenad was interviewed in the presence of his brother, (date and other details withheld).

¹⁶⁷ Human Rights Watch interview with two sisters in their early twenties, (names and other details withheld).

¹⁶⁸ Human Rights Watch interview with a medical doctor, Stamnica Home for children and adults with disabilities, October 21, 2015.

forms of violence and from torture or inhuman or degrading treatment.¹⁶⁹ Serbian national law prohibits inhuman and degrading treatment and guarantees all citizens in state care the right to humane treatment.

The CRC states that children should be protected from “all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, [and] maltreatment or exploitation....”¹⁷⁰ The European Court of Human Rights has repeatedly held governments responsible for failure to protect children from violence and neglect, whether in a domestic situation or in state care.¹⁷¹

As part of its efforts to protect persons with disabilities from all forms of violence, as stipulated in the CRPD, States parties should provide persons with disabilities and their families and caregivers with “information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.” Protection services should be age, gender, and disability sensitive.¹⁷²

The UN special rapporteur on torture has held that both seclusion and restraint can amount to torture or cruel, inhuman, or degrading treatment when used against people with disabilities in certain circumstances.¹⁷³

Under the CRC and the CRPD, Serbia should also ensure effective monitoring and mechanisms for reporting abuse. Under the CRC, States parties should ensure that

¹⁶⁹ Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A. Res. 44/25, entered into force September 2, 1990, Serbia succeeded on March 12, 2001. Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, entered into force May 3, 2008, ratified by Serbia on July 31, 2009, art. 15 and art. 16, para.1. UN Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, U.N. Doc A/RES/49/36(1984), entered into force June 26, 1987, ratified by Serbia on March 12, 2001. European Convention for the Protection of Human Rights and Fundamental Freedoms, 213 U.N.T.S. 222, entered into force September 3, 1953. Serbia became a party on March 3, 2004. See art. 3.

¹⁷⁰ CRC, art. 19, para.1.

¹⁷¹ See *Tyrer v. The United Kingdom*, Application no. 5856/72, Judgment April 25, 1978, *Others v. United Kingdom*, Application no. 29392/95, Grand Chamber judgment May 10, 2001, and *Nencheva and Others v. Bulgaria*, Application no. 48609/06, Judgment June 18, 2013.

¹⁷² CRPD, art. 16, para.2

¹⁷³ UN Human Rights Council *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 1 February 2013, A/HRC/22/53,

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf (accessed May 16, 2016)

children enjoy safe and effective means of reporting maltreatment. The CRC also guarantees children the opportunity to be heard in any judicial and administrative proceedings that affect him or her, either directly or through a representative or other “appropriate body.” States parties to the Convention on the Rights of Persons with Disabilities are obligated to monitor the convention’s implementation, including in all institutions and programs serving children with disabilities.

In its concluding observations from April 21, 2016, The UN Committee on the Rights of Persons with Disabilities called on the Serbian government to protect persons with disabilities in all institutional settings from violence, abuse, and ill-treatment of any kind.¹⁷⁴

Involuntary and Potentially Inappropriate Medical Treatment

They force me to take pills every day, during breakfast, lunch, and for dinner. In case I resist, they open my mouth with their hands and put in pills. Some of them are orange; others are white. I don’t know what they are for. They never said what they are for. Maybe they are for insanity. When I lived in another institution I didn’t have to take pills. Why do I have to take these now? My head hurts from these pills.

-Nenad, a 20-year old man with intellectual disability, October 2015

In all of the institutions visited, Human Rights Watch documented numerous cases of potentially inappropriate or forced medical treatment and intervention given to children and adults with disabilities.

Overreliance on Psychotropic Medication to Control Behavior of Children

Human Rights Watch documented that several medications, including psychotropic medications, are used on children with disabilities in Serbian institutions and small group homes, apparently as a means of dealing with behavioral issues, without the oversight or review to ensure the treatment is necessary and administered in line with the rights of children with disabilities to the highest attainable standards of health.

¹⁷⁴ CRPD, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.33.

Staff at all five institutions visited told Human Rights Watch that the majority of children and young people with disabilities in their institutions are prescribed psychotropic medications.¹⁷⁵ Mihajlo, a 17-year-old boy who lives in a small group home with thirteen other children and adults told Human Rights Watch: “Everyone who lives here except for me and another girl are on medications for their nerves.”¹⁷⁶

In three institutions, Human Rights Watch documented that many children were given combinations of the following medications: Largactil (an antipsychotic), Rivotril (a benzodiazepine), Mendilex (an anti-cholinergic), Rissar (atypical antipsychotic), Lorazepam (a benzodiazepine), Diazepam (sedative), and Amitriptyline (antidepressant).¹⁷⁷

According to Serbian website lekovi.org, which provides a list of approved medications in Serbia, Mendilex is not recommended for the use in children, Lorazepam is not recommended for children under the age of 12, and Amitriptyline is not recommended for children under the age of 16.¹⁷⁸ According to the Medicines and Medical Devices Agency of Serbia, the safety and effectiveness of Mendilex in children “have not yet been tested.”¹⁷⁹

According to the American Academy of Child and Adolescent Psychiatry, the use of psychotropic medications in children and adolescents may lead to adverse effects on neurological development, personality and character, including weight gain or movement

¹⁷⁵ According to the Serbian Ombudsman, the designated National Mechanism for the Prevention of Torture, about 80 percent of children and adults living in Veternik Institution for children and adults with disabilities receive psychiatric drugs. According to the doctor on staff, out of 127 children with disabilities in the Kolevka Home for children with disabilities Institution, 48 children are prescribed psychotropic drugs. Human Rights Watch Interview with doctor, Kolevka Home for children with disabilities, Serbia, November 18, 2015.

¹⁷⁶ Human Rights Watch interview with Mihajlo (pseudonym), small group home [date and name of the small group home withheld].

¹⁷⁷ Human Rights Watch was allowed to inspect medical files in one of the institutions visited and to see a list of psychotropic drugs prescribed to children who lived there. Staff member in two other institutions told Human Rights Watch about the most commonly medicines prescribed to children with disabilities. [Date and other details withheld].

¹⁷⁸ Mendilex, Uputstvo za lek [Prescription Information], (Available in Serbian at): <http://lekovi.org/d5co5edo/lek/mendilex.htm> (accessed April 25, 2016); Lorazepam, Uputstvo za lek [Prescription Information], (Available in Serbian at): <http://www.simptomi.rs/index.php/lekovi/4121-lorazepam-anksiolitik-benzodiazepin> (accessed April 25, 2016); Amitriptyline, Uputstvo za lek [Prescription Information], (Available in Serbian at): <http://lekoviza.com/amitriptyline-za-lecenje-depresije/> (accessed April 25, 2016).

¹⁷⁹ Mendilex, Sažetak karakteristika leka [Summary of the characteristics of the medicine], (Available in Serbian at): <http://www.alims.gov.rs/ciril/files/lekovi/smpc/515-01-6756-12-001.pdf> (accessed May 18, 2016).

disorder.¹⁸⁰ Alternative interventions to medications are especially important when there are serious side effects that occur.

Staff in institutions, including medical staff, stated that psychiatric drugs are in many cases prescribed to prevent children from harming themselves or from being aggressive to others, and also to control the behavior of children. The Ministry of Health told Human Rights Watch, in response to its concerns about the overreliance on the use of psychotropic medication to control the behavior of children, that:

Findings [of Human Rights Watch] state that psychotropic medication is given with the aim of controlling the behavior of these children, while ignoring the important fact that it is specifically for the sake and the best interest of the child to prevent aggression and auto-aggression in the first place.¹⁸¹

Ivana Cerović, a social worker at Zvečanska Center for Protection of Infants, Children, and Youth explained how members of staff are supposed to respond to children in case of self-harm or aggressive behavior, and when a decision to issue medication may be taken:

In our work, the principle is to apply other methods to calm down the child before administering the medication. Sometimes it is holding them or involving them in activities they like, sometimes we use cold compresses....Only if these methods fail do we make a decision whether the child still needs essential medicines to calm down.¹⁸²

Our research, however, suggests that quick resort to medication to control behavior may be more common in the institutions we visited.

¹⁸⁰ American Academy of Child and Adolescent Psychiatry, Guide for Community Child Serving Agencies on psychotropic medications for children and adolescents, February 2012, http://www.aacap.org/app_themes/aacap/docs/press/guide_for_community_child_serving_agencies_on_psychotropic_medications_for_children_and_adolescents_2012.pdf (accessed May 16, 2016).

¹⁸¹ Ministry of Health of Republic of Serbia, Letter to Human Rights Watch, May 9, 2016. Appendix 2.

¹⁸² Human Rights Watch e-mail communication with Ivana Cerović, Zvečanska Center for Protection of Infants, Children, and Youth, February 17, 2016.

For example, a 19-year-old woman with psychosocial disability told Human Rights Watch that she had observed that staff were quick to use medication to address aggressive behavior in the institution where she lives:

A year ago or so, they would often tie hands of my friend and give her an injection in case she was nervous. For example, last year she tore down the curtains and they tied her down to a bed and gave her an injection. Now, if someone is aggressive, they give them medication to calm down. They give me drugs too when I am nervous.¹⁸³

A medical doctor in Sremčica Home for children and adults with disabilities explained that, according to institutional policy, physical restraints are not allowed in the institution in the case of behavior considered to be harmful or aggressive: “We use drugs in case of self-harm. We regulate this [self-harm or aggressive behavior] by medication, not restraints.”¹⁸⁴

A physician in one institution explained, “Most of them are prescribed psychiatric drugs because of behavioral outbursts.”¹⁸⁵ Staff member in another institution said, “Children are being prescribed medicines to stabilize them in a neurological way.”¹⁸⁶

Staff in institutions can administer medication at their own discretion, due to standing prescriptions from psychiatrists allowing the administration of the medications “as needed”.¹⁸⁷

Staff in institutions also recognized the lack of knowledge on alternatives to support children or adults who may be exhibiting self-harming or otherwise “undesirable” behavior as perceived by staff. For example, an educator in a small group home, told Human Rights

¹⁸³ Human Rights Watch interview with a 19-year-old woman with psychosocial disabilities living in a Serbian institution [date and other details withheld], Serbia.

¹⁸⁴ Human Rights Watch interview with medical doctor [name and other details withheld], Serbia.

¹⁸⁵ Human Rights Watch interview with medical doctor [name and other details withheld], Serbia.

¹⁸⁶ Human Rights Watch interview with institution staff, Zvečanska Center for Protection of Infants, Children, and Youth, November 17, 2015.

¹⁸⁷ Human Rights Watch reviewed medical files in one institution visited and noted that psychiatrists sometimes prescribed the use of sedatives “as needed”, leaving it to the discretion of the institution staff. Staff in two other institutions confirmed to Human Rights Watch the practice of the psychiatrists prescribing the use of psychotropic drugs “as needed”.

Watch, “We need more information and feedback on what to do in cases of aggression and attacks. We do have those challenges.”¹⁸⁸ A staff member in Zvecanska Institution acknowledged that, “Usually aggression is a sign that the child is craving something. That we need to pay more attention to the child.”¹⁸⁹

Staff in two institutions visited stated that the lack of staff contributed to overreliance on high dosages of psychotropic medication for children, as a means for small numbers of staff to manage a large number of children and adults. A psychologist from Kolevka Home for children with disabilities told Human Rights Watch, “Maybe medications would be reduced if we had more ‘special education therapists’ (or experts trained in how best to support children with disabilities).”¹⁹⁰ The doctor from the institution in Sremčica had a similar view: “There is one special education therapist per 25 residents. It is impossible to devote [time to each child]. An individual approach is simply not possible. The need for psychotropic drugs would be significantly reduced if we only had more people on staff.”¹⁹¹

All five institutions visited by Human Rights Watch had a physician and medical nurses on staff. Veternik Institution for children and adults with disabilities had a psychiatrist and a dentist as well. Other institutions do not have a psychiatrist on staff. Medical personnel and caregivers in these institutions and small group homes are allowed to administer sedatives and other psychiatric medications as prescribed by a psychiatrist.¹⁹² According to the institution staff, psychiatrists visit the institutions every second week or once per month to examine the children and make adjustments to their medications.

According to the Ministry of Health, there is no independent and periodic monitoring of medical treatment, including prescriptions, for children and young people in institutions.¹⁹³

¹⁸⁸ Human Rights Watch interview with educator, small group home in Aleksinac Serbia, November 19, 2015.

¹⁸⁹ Human Rights Watch interview with institution staff, Zvečanska Center for Protection of Infants, Children, and Youth, Serbia, November 17, 2015.

¹⁹⁰ Human Rights Watch interview with psychologist, Kolevka Home for children with disabilities, Serbia, November 18, 2015.

¹⁹¹ Human Rights Watch interview with medical doctor, Sremčica Home for children and adults with disabilities, November 16, 2015.

¹⁹² Human Rights Watch interview with medical doctor, Institution for children and adults with disabilities in Veternik, Serbia, October 20, 2015; Human Rights Watch interview with medical doctor, Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

¹⁹³ Human Rights Watch interview with Slađana Đukić, Ministry of Health of Republic of Serbia, November 30, 2015.

The UN Committee on the Rights of Persons with Disabilities called on Serbia to “prohibit all forms of coercive treatments against adults and children with disabilities, including physical and chemical restraints as well as excessive antipsychotic therapy and isolation.”¹⁹⁴

Consent to treatment

Eight children and young people told Human Rights Watch about being either forced to take medication or feeling they have no other option but to take medication given to them by their caregivers.

Six children and young people interviewed complained about headaches or stomach pain due to the medication they take: “I must take drugs for sleep and my nerves. Every single day. I always feel awful afterward.”¹⁹⁵ One 20-year-old woman with intellectual disabilities told Human Rights Watch about being forced to take medication against her will: “I must take sleeping pills to help me with my nerves and pills for epilepsy. First they ask me to take pills and if I refuse, they will force me by holding me down to swallow them.”¹⁹⁶

Human Rights Watch sought clarity from authorities with respect to who according to Serbian law should give consent for medical treatment of children with disabilities in institutions, but did not receive any relevant information. Human Rights Watch is concerned at this apparent lack of clarity, and, from what it observed, a failure to provide children with adequate information about the medication or the opportunity to participate in decisions about what medication they should take. At a minimum, steps should be taken to explain to the child what the medication is, why it is necessary and appropriate, and the potential side effects.

While international law recognizes that children can be given treatment on the consent of a parent or a guardian, article 12 of the Convention on the Rights of the Child also highlights

¹⁹⁴ Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.29.

¹⁹⁵ Human Rights Watch interview with a 20-year-old woman with intellectual disability, Serbia, October 21, 2015.

¹⁹⁶ Human Rights Watch interview with Dina (pseudonym), Stamnica Home for children and adults with disabilities, Serbia, October 21, 2105.

the importance of children's participation, providing for children to express their views and to have such views seriously taken into account, according to age and maturity.¹⁹⁷ The Committee on the Rights of the Child, in its General comment on the right of the child to the enjoyment of the highest attainable standard of health, explained that article 12 includes views of children on all aspects of their health, "including, for example, what services are needed, how and where they are best provided [...]."¹⁹⁸

The Committee further noted that children who are particularly vulnerable to discrimination are also often less able to exercise their autonomy to decision-making on their health issues.¹⁹⁹ The Committee recommended development and implementation of supportive policies so that "children, parents and health workers have adequate rights-based guidance on consent, assent and confidentiality."²⁰⁰

Finally, the Committee warned against over-medicalization and institutionalization of children with psychosocial disabilities, and urged governments "to undertake an approach based on public health and psychosocial support to address mental ill-health among children and adolescents and to invest in primary care approaches that facilitate the early detection and treatment of children's psychosocial, emotional and mental problems."²⁰¹

Denial of Sexual and Reproductive Health Rights

Medical staff at three institutions told Human Rights Watch about invasive medical interventions conducted on young women with disabilities to prevent or terminate pregnancy and for cancer screening. They acknowledged carrying out these procedures without the free and informed consent of these women but said their guardians had given consent. Under Serbian law, healthcare providers do not need to obtain consent of a

¹⁹⁷ See general comment No. 12 (2009) on the right of the child to be heard, *Official Records of the General Assembly, Sixty-fifth Session, Supplement No. 41 (A/65/41)*,

¹⁹⁸ See general comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), para.19.

¹⁹⁹ *Ibid.*, para.21.

²⁰⁰ *Ibid.*

²⁰¹ *Ibid.*, para.38

person who is stripped of legal capacity and placed under guardianship.²⁰² The interventions included the insertion of intrauterine devices (for birth control), administration of pap smear tests (Papanicolaou test, a screening procedure for cervical cancer), and termination of pregnancy. According to the staff, some women were put under general anesthesia for some of the procedures to ensure they would not resist²⁰³ --the use of general anesthesia for these medical procedures is unusual and unnecessary. It is unclear whether any efforts were made to engage the women in discussions about these medical interventions.

For example, when Human Rights Watch researchers asked the doctor in Sremčica Home for children and adults with disabilities if there were any efforts to engage and get the informed consent of the woman whose pregnancy was terminated in 2014, the doctor said, “Her consent was not required, just the consent of the guardian. Her sister is her guardian and she gave the consent.”²⁰⁴ The same doctor told Human Rights Watch that 20 young women living in Sremčica Home for children and adults with disabilities have intrauterine devices for birth control, with the guardian’s consent: “Currently, two other women are in the process of getting intrauterine devices.”²⁰⁵

Doctors in three institutions explained that they put the women under general anesthesia if they do not consent to a medical intervention: “When female residents don’t cooperate, for example, during a sonogram or the administration of a Pap smear test, you have to put them under anesthesia to conduct the intervention.”²⁰⁶ Another medical doctor told Human Rights Watch that sexual relationships are not prohibited but that the reproduction is controlled, “The last time we had someone pregnant was in 1997.”²⁰⁷

²⁰² Human Rights Watch interview with medical doctor in Stamnica Home for children and adults with disabilities, October 21, 2015; Human Rights Watch interview with medical doctor in the Institution for children and adults with disabilities in Veternik, October 20, 2015, Human Rights Watch interview with a medical doctor, Sremčica Home for children and adults with disabilities, November 16, 2015. The staff in all three institutions did not provide Human Rights Watch with the exact number of young women who were subjected to these treatments.

²⁰³ Ibid.

²⁰⁴ Human Rights watch with a medical doctor, Sremčica Home for children and adults with disabilities, November 16, 2015.

²⁰⁵ Ibid.

²⁰⁶ Ibid.

²⁰⁷ Human Rights Watch interview with a medical doctor, Veternik Institution for children and adults with disabilities, October 20, 2015.

In an April 2016 meeting with the Ministry of Health of the Republic of Serbia in Geneva, Switzerland, Human Rights Watch raised concerns about involuntary interventions against women with disabilities who live in institutions. Vladimir Cakarevic, from the Ministry of Health, told Human Rights Watch, “According to Serbian law, we only need the consent of the guardian to perform any medical interventions for people stripped of legal capacity.”²⁰⁸

The UN Committee on the Rights of Persons with Disabilities recommended that Serbia should investigate and prohibit “all medical interventions without the prior consent of persons with disabilities and to provide sufficient remedies and compensation to those subjected to such procedures.”²⁰⁹ The Committee further urged Serbia to “take all necessary measures to ensure their right to free, prior and informed consent for any kind of treatment that may affect a person with a disability, regardless of her/his legal capacity.”²¹⁰ Support for decision-making regimes for persons with disabilities should be provided when necessary.²¹¹

As a sign of the seriousness with which the Committee approaches this issue, it required Serbia to report back by April 2017 on the steps taken to fulfill these specific recommendations.²¹²

Lack of Education

I used to go to school, but since I arrived here seven or eight years ago, I stopped.

—Miroslav, 17-year-old boy with physical and intellectual disabilities, Stamnica Home for Children and Adults with Disabilities October 2015.

Children and young people with disabilities living in institutions in Serbia have little or no access to education. Children who do receive education attend specialized schools or classrooms only for children with disabilities. Some children receive education within the

²⁰⁸ Human Rights Watch interview with Serbian delegation to the UN Committee on the Rights of Persons with Disabilities, Geneva, Switzerland, April 5, 2016.

²⁰⁹ Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.35.

²¹⁰ Ibid., para. 39.

²¹¹ Ibid.

²¹² Ibid., para.71.

institution. The majority of children in the “wards for the most severely disabled” do not receive any education.

For example, none of the 22 children and 69 young people with disabilities in the Stamnica Home for Children and Adults with Disabilities attend school. “We put the television on or they spend their time in the workshop [drawing or learning life skills],” a caregiver working in the institution explained when describing how children spend their days.²¹³

Human Rights Watch researchers visited all institutions during school hours and found a large number of primary and secondary school age children in the institution, rather than at school. In most cases, institution staff claimed that the children’s health was too fragile for them to be in school. However, some institution staff recognized the problematic exclusion of children with disabilities from education: “Not all children go to school every day. For example, there is this one boy who goes only once per week. It doesn’t make any sense to me, but that’s what the school decided,” she explained.²¹⁴

In four of the institutions visited, Human Rights Watch found that many children are excluded from school because they did not start early enough, according to the staff. Staff at Kolevka Home for children with disabilities explained that many children between the ages of 13 and 15 do not go to school because they are “now beyond the age to enter school.”²¹⁵ Human Rights Watch, for example, met Ivana, a 14-year-old girl with autism, in Kolevka Home for children with disabilities. The caregiver explained, “She doesn’t go to a school at all because they didn’t send her when she was younger and now it is too late. There are a lot of children like that.” Out of 167 children who live in Kolevka, only 23 go to school.²¹⁶

Under the Law on the Fundamentals of the Education System, every child from the age of 6 years and six months to 7 years and six months must be enrolled in school. A child older

²¹³ Human Rights Watch interview with staff in the Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

²¹⁴ Human Rights Watch interview with a caregiver in Sremčica Home for children and adults with disabilities, November 16, 2015.

²¹⁵ Human Rights Watch interview with staff in Kolevka Home for children with disabilities, November 18, 2015.

²¹⁶ Ibid.

than 7 years and six months can be enrolled in first or another relevant grade following a knowledge test.²¹⁷ According to the Ministry of Education, every child can and must be enrolled in school, regardless of whether the child “started on time.”²¹⁸

According to disability experts in Serbia the more severe the disability the lower the likelihood a child who lives in an institution would be included in the education system. Staff in institutions often told Human Rights Watch that only children “with better prospects” will be included in schools and preschools: “For those deemed to be able to go to school, they are in school. First, we included the best children. We can’t include them all.”²¹⁹

Human Rights Watch did meet some institution staff that seemed to put a great effort to include children with disabilities in schools, in the face of resistance from school personnel. For example, a psychologist from Kolevka told Human Rights Watch, “When we first were trying to enroll children in schools, the teacher from the special school said, ‘We’ll just come to the institution and teach the children.’ We said no, they should go to school itself.”²²⁰

The Serbian delegation to the UN Committee on the Rights of Persons with Disabilities reported that only 40 percent of all children with disabilities living in Serbian institutions are included in the education system.²²¹ Children with disabilities who are enrolled in schools are enrolled in segregated settings and go to special schools for children with disabilities. For example, out of 49 children with developmental and intellectual disabilities who live in Sremčica Home for children and adults with disabilities, 32 are included in special schools some 10-20 kilometers away from the institution. This is despite the fact that there is a mainstream school located just across the street from the institution’s building. According to the director of the institution, the reason why children

²¹⁷ “If a child older than seven and a half years of age has not been enrolled in the first grade due to illness or for other reasons, this child may be enrolled in the first or a relevant grade following the test in previously acquired knowledge.” Law on Fundamentals of the Education System, art. 98.

²¹⁸ Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1.

²¹⁹ Human Rights Watch interview with staff in Kolevka Home for children with disabilities, Serbia, November 18, 2015.

²²⁰ Human Rights Watch interview with psychologist in Kolevka Home for children with disabilities, Serbia, November 18, 2015.

²²¹ Human Rights Watch interview with Serbian delegation to the UN Committee on the Rights of Persons with Disabilities, Geneva, Switzerland, April 5, 2016.

don't go to the mainstream school in their community is due to the lack of capacity within the school: "Teachers are not trained to work with children who have intellectual or psychosocial disabilities."²²²

In a letter to Human Rights Watch dated May 19, 2016, the Ministry of Education recognized the need to include children who live in institutions in the education system and explained that this is envisaged in the 2016 work plan of the Ministry's Group for Social Inclusion.²²³ The Ministry explained that the first step was to collect accurate data on children who are excluded from the education system.

In response to Human Rights Watch's concerns about accountability for guaranteeing all children with disabilities, including those living in state institutions, access to inclusive education, the Ministry of Education wrote to Human Rights Watch:

Legal guardians of children are employees of the Center for Social Work and it is implied they know the rules. According to the law, a parent or a guardian is obliged to enroll the child in school. Also, the school is obliged to report the parent/guardian to the educational inspection, if the school has information about a child not attending school. The local government bears the direct responsibility for enrollment of all children in compulsory education.²²⁴

Human Rights Watch documented that the majority of children who are enrolled in school do not spend more than two to three hours per day in school or attend school only a few times per week. For young people with disabilities, secondary education is not widely available and, where it is available, it is limited to vocational training. For example, in Kolevka Home for children with disabilities the oldest child to be enrolled in the education system is a 12-year-old, "We hope in the future some of the children will be able to go to secondary school. There is basic vocational training in some places, to learn to be a florist and things like that."²²⁵

²²² Human Rights Watch with the director of the Sremčica Home for children and adults with disabilities, November 16, 2015.

²²³ Ministry of Education of Republic of Serbia, Letter to Human Rights Watch, May 19, 2016. Appendix 2.

²²⁴ Ibid.

²²⁵ Human Rights Watch interview with staff in the Kolevka Home for children with disabilities, Serbia, November 18, 2015.

According to the director of the small group home in Aleksinac, there is no secondary education available for children who live in the small group home.²²⁶

Right to education

International human rights law makes clear that all children have a right to free, compulsory primary education, free from discrimination.²²⁷ The CRC guarantees the right of the child to education, progressively and on the basis of equal opportunity.²²⁸ The CRPD guarantees persons with disabilities access to inclusive primary and secondary education in the communities where they live. Reasonable accommodation of individuals' educational requirements should be provided.

The Office of the High Commissioner for Human Rights, the United Nations' human rights agency, states that:

The right of persons with disabilities to receive education in mainstream schools is included in article 24 (2) (a), which states that no student can be rejected from general education on the basis of disability. As an anti-discrimination measure, the "no-rejection clause" has immediate effect and is reinforced by reasonable accommodation... forbidding the denial of admission into mainstream schools and guaranteeing continuity in education. Impairment based assessment to assign schools should be discontinued and support needs for effective participation in mainstream schools assessed.... The legal framework for education should require every measure possible to avoid exclusion.²²⁹

²²⁶ Human Rights Watch interview with Jasna Nikolić, director of the small group home in Aleksinac, Serbia, November 19, 2015.

²²⁷ United Nations Economic and Social Council, "Preliminary report of the Special Rapporteur on the right to education, Ms. Katarina Tomasevski, submitted in accordance with Commission on Human Rights resolution 1998/33," E/CN.4/1999/49, 13 January 1999, <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G99/101/34/PDF/G9910134.pdf?OpenElement> (accessed August 5, 2015).

²²⁸ CRC, arts. 28(1), 29(1).

²²⁹ United Nations Human Rights Council, "Thematic Study on the right of persons with disabilities to education," Report of the Office of the United Nations High Commissioner for Human Rights, A/HRC/25/29, December 18, 2013. Report of the Office of the United Nations High Commissioner for Human Rights (A/HRC/25/29) paras.26-27.

Serbia has adopted laws committing to respect and fulfill international and regional obligations to provide free, compulsory primary education available to all children on an equal basis. The Serbian “Law on the Fundamentals of the Education System” prohibits discrimination against persons with disabilities in access to education. One of the law’s key principles is to ensure “opportunities for children, students, and adults with disabilities, regardless of their financial status, to gain access to all levels of education in institutions, and for persons living in social welfare institutions, sick children and students, to exercise their right to education while in an institution, hospital or receiving treatment at home.”²³⁰ The 2015 amendments to the law further introduced an obligation to reduce drop-outs from schools, especially for persons with disabilities “in accordance with the principles of inclusive education.”²³¹ The law further sets minimum inclusive education standards, such as specialized teacher education,²³² reasonable accommodation,²³³ and other curricular changes²³⁴ to ensure that children with disabilities are included in schools.

The law recognizes the right of children with disabilities to inclusive education “within the regular system with individual or group additional assistance” or “in special preschool group or school.”²³⁵

The Strategy of the Education System 2020, adopted in 2012, reiterates the right to inclusive education, equal opportunities for all children, non-discrimination, inclusion, enrollment of all children, the best interest of the child, individual educational plans, expert teams for inclusive education and support teams for children, inclusion of parents in the planning, realization and evaluation of individual plan of support and cooperation with local community.²³⁶

²³⁰ Law on Fundamentals of the Education System, Official Gazette of the Republic of Serbia, No. 72/2009, 52/2011, 55/2013, 35/2015, and 68/2015, art. 3, para.3(4)

²³¹ Ibid., art. 3, para.3(5)

²³² Ibid., art. 116.

²³³ See for example Law on Fundamentals of the Education System, art. 102 on accessible books.

²³⁴ See for example Law on Fundamentals of the Education System, art. 77 on individual education plans.

²³⁵ Law on Fundamentals of the Education System, art. 3; Article 10 of the Law on Primary education guarantees a child with disability the right to education in mainstream school “together with other children,” unless it is in the child’s best interest to be educated in a school for children with disabilities. See: Law on Primary Education, Official Gazette of the Republic of Serbia, No. 55/2013, art. 10, (Available in Serbian at):

http://www.paragraf.rs/propisi/zakon_o_osnovnom_obrazovanju_i_vaspitanju.html [accessed: April 18, 2016].

²³⁶ The Strategy of the Education System 2020 (Available in Serbian at):

<http://www.vtsnis.edu.rs/StrategijaObrazovanja.pdf> (accessed May 10, 2016)

The Action Plan for Inclusive Education for the period 2016 - 2020, which includes transformation of special schools for children with disabilities and special classes in mainstream schools, is yet to be adopted by the government.²³⁷

In April 2016, the Committee on the Rights of Persons with Disabilities urged Serbia to give special attention to children with multiple disabilities and children with disabilities who live in institutions in the Action Plan.²³⁸ Specifically, the Committee asked Serbia to “take immediate steps to ensure that all persons with disabilities have access to inclusive and quality primary, secondary and tertiary education and that reasonable accommodation, in accordance with established individual education plans, is provided in mainstream education.”²³⁹ It further recommended training on inclusive education for teachers and other education professionals and urged Serbia to make all secondary and tertiary education facilities accessible: The Committee stressed that denial of reasonable accommodation constitutes discrimination.²⁴⁰

Lack of engagement by guardians in the lives of children

Under Serbian law, a legal guardian is responsible for protecting and caring for the child, including taking care of a child’s upbringing and education.²⁴¹ The guardian is also required to keep in mind the child’s best interests and must visit the child and directly report about conditions in which a child lives to the Center for Social Work.²⁴² Guardians can be family members, friends, or directors of institutions and staff at the Centers for Social Work. The latter option – a staff member of the Centers for Social Work – acted as guardians for the majority of children and young people with disabilities in institutions Human Rights Watch visited.

According to local activists, institution staff, and children and young people with disabilities interviewed by Human Rights Watch, guardians almost never visit or interact

²³⁷ Ministry of Education of Republic of Serbia, Letter from April 28, 2016. Appendix 1.

²³⁸ Committee on the Rights of Persons with Disabilities, Concluding observation on the initial report of Serbia, CRPD/C/SRB/CO/1, April 21, 2016, para.49.

²³⁹ Ibid., para.51.

²⁴⁰ Ibid., para.51.

²⁴¹ Family Law, art. 136, para. 1.

²⁴² Ibid., art. 136, para.3.

with children who live in institutions, particularly when the guardian is a staff member at a Center for Social Work.²⁴³ For example, a caregiver from Sremčica Home for children and adults with disabilities told Human Rights Watch how the legal guardian of a young man with intellectual and developmental disabilities who has lived in the institution since he was a baby had visited him only once in the 17 years that he has lived in that institution.²⁴⁴ A social worker in the same institution confirmed the lack of contact between guardians and children, “Some guardians visit children yearly, some never.”²⁴⁵

Such limited contact is problematic for two reasons. Firstly, there is no effective monitoring to ensure the child is protected against abuse and neglect, as required by the law. Secondly, limited or no contact at all compromises the ability of a child to receive education or to leave an institution. For example, a social worker in Sremčica Home for children and adults with disabilities complained about the lack of engagement from legal guardians and the impact it has on returning children to their families:

They [guardians] should visit the residents more often. This would provide us with more opportunities to exchange information but also they could help to empower families to take children back. For example, we have children here who are from Niš and it is hard for us to engage with their families who are more than 200 kilometers away from our institution.²⁴⁶

A study from March 2016 linked low enrollment of children with disabilities who live in institutions in the education system to the lack of engagement of guardians in the lives of children.²⁴⁷ According to the Serbian law, it is the primary obligation of parents and legal guardians to enroll children with disabilities in schools.

²⁴³ Human Rights Watch interview with Nevena (pseudonym), a former volunteer in one of the five institutions Human Rights Watch visited, Serbia, November 30, 2015; Human Rights Watch interview with social worker, Stamnica Home for children and adults with disabilities, October 21, 2015. Human Rights Watch interview with a medical nurse (name and other details withheld), Veternik Institution for children and adults with disabilities, October 20, 2015. Human Rights Watch interview with institution staff in the Kolevka Home for children with disabilities, Serbia, November 18, 2015.

²⁴⁴ Human Rights Watch interview with institution staff, Sremčica Home for children and adults with disabilities, November 16, 2015.

²⁴⁵ Ibid.

²⁴⁶ Ibid.

²⁴⁷ Biljana Janjić, Kosana Beker, Exclusion and segregations of children with disabilities living in institutions from the education system [In Serbian: Isključivanje i segregacija dece sa smetnjama u razvoju na rezidencijalnom smeštaju iz obrazovnog Sistema] March 2016, pp.40-41.

One reason for this lack of guardian-child interaction is the fact that legal guardians in Serbia are assigned to children according to a child's home residence, not according to the place of the institution where a child lives. Sometimes this means that a legal guardian is someone who lives more than 350 kilometers away from the child. For example, in Kolevka Home for children with disabilities, legal guardians of two twin toddlers are based even outside of Serbia, in Bosnia and Herzegovina. According to institution staff, their guardian has never visited these two boys.²⁴⁸

Limited Freedom of Movement

Seven young people with disabilities living in institutions interviewed by Human Rights Watch complained about the lack of freedom of movement. For example, two sisters diagnosed with intellectual disabilities told Human Rights Watch they are allowed to leave the institution only on the weekends:

We don't have freedom. That's one thing I dislike the most about being here. For example, we have to wake up every day at 7 a.m. – only on the weekends we can sleep how long we want. Then, forget about making a choice on what to eat.²⁴⁹

A 19-year-old woman with psychosocial disability who lives in another institution complained about the lack of freedom of movement, "It is prohibited to go to the city. They told me I need a paper from the Center to go into the city."²⁵⁰ She also told Human Rights Watch that family members can visit only until four or five in the afternoon: "Once my sister came to see me a bit later, around 6 p.m. and they did not allow her to visit me."²⁵¹

Marko, a 30-year-old young man who has lived in institutions since he was a child, explained: "It depends on how much they allow us. For example, they tell us we can leave the institution but that we have to be back by 5 or 6 p.m. In case you are late, you are

²⁴⁸ Human Rights Watch interview with institution staff, Kolevka Home for children with disabilities, Serbia, November 18, 2015.

²⁴⁹ Human Rights Watch interview with two young women (names and other details withheld), Serbia.

²⁵⁰ Human Rights Watch interview with a 19-year-old woman with psychosocial disabilities living in a Serbian institution (name and other details withheld), Serbia.

²⁵¹ Ibid.

grounded and can't leave for two months.”²⁵² Slobodan, 18, said, “I can't go to a market. When I lived with a foster family I was allowed to, but here I am not.”²⁵³ Mile, a 20-year-old man explained that he can leave the complex of the institution “only if accompanied by educators, otherwise I can't leave at all.”

Denial of Legal Capacity

Let me tell you something. I want to get away from here. When I am 18, I am going to leave this place and live in an apartment.

—Natalia, 15-year-old with intellectual disability in small group home²⁵⁴

Under Serbian law, children lack legal capacity. In exceptional cases, a court can recognize full legal capacity of children between 16 and 18 years of age.²⁵⁵ Every person when turning 18 has the right to full legal capacity.²⁵⁶

For persons with disabilities who live in institutions in Serbia, this right is often denied upon reaching adulthood (age 18). Human Rights Watch research revealed that persons with disabilities in Serbia are often stripped of their right to legal capacity and the right to make decisions on medical treatment or the decision to leave an institution under two existing procedures: (1) guardianship and (2) so called “extended parental rights.” In both cases, the person is deprived of the right to make decisions about his or her basic rights and instead the person's parents or legal guardians make all decisions for the person, including where and with whom to live. As of December 2014, more than 19,000 people with disabilities in Serbia who are deprived of legal capacity have been placed under guardianship or subjected to extended parental rights. Only 5.7 percent or 608 adults are only partially deprived of legal capacity meaning that they can make some choices by themselves.²⁵⁷

²⁵² Human Rights Watch interview with Marko, Serbia, November 16, 2015.

²⁵³ Human Rights Watch interview with Slobodan (pseudonym), Serbia, November 16, 2016.

²⁵⁴ Human Rights Watch interview with Natalia (pseudonym), Aleksinac, Serbia, November 19, 2015.

²⁵⁵ Family Law, art. 11, para. 3.

²⁵⁶ Ibid., art. 11, para. 1.

²⁵⁷ Committee on the Rights of Persons with Disabilities, Replies of Serbia to the list of issues, February 5, 2016, para.57.

According to Serbia's Family Law, an adult person who is, "as a result of illness or mental and physical disability, incapable of normal reasoning and therefore unable to care independently for his or her own rights and interests" can be fully deprived of his or her legal capacity and placed under guardianship.²⁵⁸ In this case, the person is considered to have the rights of a child below the age of 14 and is placed under full guardianship; legal guardians make all decisions for them.²⁵⁹

Furthermore, if a person "directly threatens his or her own rights and interests or the rights and interests of other persons," he or she can be partially deprived of legal capacity and placed under partial guardianship.²⁶⁰ In this case, the person is considered to have the rights of an "older child" (from age 14 until 18),²⁶¹ and the Court specifies the activities that a person partially deprived of legal capacity is deemed capable of independently undertaking, as well as the activities for which a guardian should instead make decisions.²⁶²

In addition to guardianship, according to the Family Law, parental rights can be extended for a person after turning 18 until the age of 26 in case the person is deemed by a court to be "incapable of taking care of and protecting his or her rights, or if he/she threatens his or her rights and interests with his or her actions, as a result of illness or mental and physical disabilities."²⁶³ In this case, a court also makes a decision on full or partial legal capacity restrictions and extending the rights of parents to make decisions instead of the person concerned.²⁶⁴

Young adults with psychosocial or intellectual disabilities in Serbia told Human Rights Watch that they want to live with their families or in the community, but that they have no choice in deciding where to live or when to leave an institution. For example, a 20-year-old

²⁵⁸ Family Law, art. 146.

²⁵⁹ Ibid.

²⁶⁰ Ibid., art. 147.

²⁶¹ Ibid., art. 147, para.2.

²⁶² Ibid., art. 147, para.3.

²⁶³ Ibid., art. 85.

²⁶⁴ Law on Non-Contested Procedure, Official Gazette of the Republic of Serbia, No. 46/95, 18/2005, 85/2012, 45/2013, 55/2014, 6/2015, and 106/2015, art. 73. (Available in Serbian at): http://www.paragraf.rs/propisi/zakon_o_vanparnicnom_postupku.html (accessed February 3, 2016).

young man who has lived in an institution since he was 10 years old told Human Rights Watch, “I would love to see my parents every day, to wake up in the morning and see them, to have coffee with them. But the Center [for Social Work] does not allow it. We cannot do anything without the Center’s permission.”²⁶⁵

Dina, a 20-year-old young woman who has lived in Stamnica Home for children and adults with disabilities for two years, told Human Rights Watch, “It is my dream to leave this place. The sooner, the better. The Center knows that. But they tell me, ‘You should stay here.’ I would just love to be somewhere where there are more people I can talk with.”²⁶⁶

Right to Legal Capacity for Adults with Disabilities

The right to live in the community for persons with disabilities is intricately linked to the right to exercise legal capacity guaranteed by article 12 of the CRPD. Individuals with disabilities are particularly vulnerable to placement in institutions because they are often deprived of their ability to make important life decisions. For the same reason, often they are denied the choice to leave institutions. Therefore, to ensure the right of children and young people to live in the community, states should also respect the right to the full exercise of legal capacity upon reaching adulthood.

Under international human rights law, every person has the right to recognition as a person under the law.²⁶⁷ This recognition as a person comes with the presumption that a person can make life decisions on his or her own behalf. Accordingly, article 12 of the CRPD provides that “States parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and “shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”²⁶⁸

²⁶⁵ Human Rights Watch interview with Bojan (pseudonym), Sremčica Home for children and adults with disabilities, Serbia, November 17, 2015.

²⁶⁶ Human Rights Watch interview with Dina (pseudonym), Stamnica Home for children and adults with disabilities, Serbia, October 21, 2015.

²⁶⁷ International Covenant on Civil and Political Rights (ICCPR), adopted December 16, 1966, G.A. Res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171, entered into force March 23, 1976, art. 16; Universal Declaration of Human Rights (UDHR), adopted December 10, 1948, G.A. Res. 217 A(III), U.N. Doc. A/810 at 71 (1948), art. 6.

²⁶⁸ CRPD, art. 12(2); CRPD, art. 12(3).

The UN General Assembly in 1971 and 1991 took for granted that individuals with certain degrees of intellectual or mental disability would not be capable of exercising some rights on their own and needed to be protected. Courts could thus deprive individuals of the capacity to make important decisions and exercise rights on their own behalves.²⁶⁹

The CRPD fundamentally shifts the discourse on legal capacity by removing “deprivation” and “protection” from its provisions. The text of article 12 instead creates the assumption that persons with disabilities can act in their own best interests and that, when needed, they should be given support to do so.

This assisted-decision making system should be a regime of support for the individual’s exercise of rights, a process by which the will and the preferences of the person are fully respected. Within this support system, a state should ensure safeguards to prevent abuse. These safeguards should ensure that the support provided is proportionate to the person’s circumstances, limited in duration, free from conflicts of interest, and subject to regular, impartial review by a judicial body.²⁷⁰

In its April 2016 review, the UN Committee on the Rights of Persons with Disabilities urged Serbia to replace its guardianship system with “supported decision-making regimes which respect the person’s autonomy, will and preferences, and establish transparent safeguards.”

As the state supports the right of children with disabilities to live in the community, it should also review its own procedures for placement of adults into institutions, which may amount to a deprivation of liberty, and require adequate safeguards to protect against

²⁶⁹ UN General Assembly, The Protection of persons with mental illness and the improvement of mental health care, A/RES/46/119, adopted at the 75th plenary meeting, December 17, 1991, paras. 6,7.

²⁷⁰ CPRD, art. 12(4).

arbitrary deprivation.²⁷¹ The guarantees of liberty and security of the person, and the right to challenge any deprivations of those liberties, is set out in article 5 of the ECHR and article 9 of the ICCPR which states, “No one shall be subjected to arbitrary arrest or detention” and “no one shall be deprived of his liberty except on such grounds and in accordance with such procedures as are established by law.”²⁷²

Article 14 of the CPRD provides additional protection against deprivation of liberty for persons with disabilities: the right not to be detained on the basis of the existence of a disability. There should therefore be some basis, one that does not discriminate based on disability, underlying any deprivation of liberty.

²⁷¹ The European Court of Human Rights recognizes people who have been placed in institutions without their consent, if the staff at the institution exercises “complete and effective control over [their] care and movements” have been deprived of their liberty within the meaning of Art. 5 of the European Convention on Human Rights (See: European Court of Human Rights, *H.L. v. United Kingdom* (no. 45508/99) Judgment of October 5, 2004, para.91. See also European Court of Human Rights, *Storck v. Germany*, (no. 61603/00) Judgment of July 16, 2005, for state responsibility for those deprived of their liberty in private institutions paras. 74, 89.) Additionally, a person is deprived of liberty when placed in an institution against his or her will even if that person is not actively resisting institutionalization, the facility is not locked or lockable, or the person has been permitted to frequently leave the facility unsupervised. Thus, under the European Convention on Human Rights, the prohibition on arbitrary detention applies even to those facilities that claim they are not detaining individuals, as long as those housed within them are not free to leave.

²⁷² ICCPR, art. 9(1).

Recommendations

To the Serbian Government, Including the Ministries of Social Policy, Health, Education, and Finance

Protect children and young people with disabilities in institutions from harm and abuse, through the following measures:

- Ensure the Rulebook on Prohibited Practices of the Employees in Social Protection is enforced so that children in institutions are free from all physical or psychological abuse and neglect and hold anyone responsible for such abuse or neglect to account.
- Create accessible and effective mechanisms for children with disabilities in state institutions to report abuse without risk of repercussions. This includes informing children in an accessible manner about their rights and ways in which to file complaints and receive psychological and legal assistance. Ensure children's complaints are reviewed and addressed promptly and impartially.
- Eliminate the isolation of children on the basis of their disability. To prevent the spread of contagious diseases among children living in institutions, ensure that all children receive necessary vaccinations and provide access to health clinics or doctors so that children who present with symptoms of infectious or contagious diseases can receive appropriate treatment.
- For as long as certain children with disabilities are cared for in “wards for the most severely disabled”, ensure that they enjoy the same rights as all other children.
- For as long as children with disabilities live in state institutions, ensure that they have access to inclusive education, adequate health care, rehabilitation, and play.
- Ensure all efforts are undertaken to toilet train children with disabilities who live in institutions, including guidance for institution staff on how to toilet train children with intellectual and developmental disabilities.
- Ensure persons with disabilities enjoy their right to health and the right to free and informed consent to medical treatment is respected.

- Ensure the best interest of the child is respected when deciding on necessary and appropriate medical treatment and that the views of children are heard and taken into account. Obtain consent from children for when possible.
- End the use of any inappropriate psychiatric treatments as a means of controlling a child's behavior. Instead, train staff in alternative methods and skills to de-escalate behavior.
- Establish an independent oversight mechanism to protect children and young people with disabilities from forced medication to control their behavior, and from medication that might be prejudicial to their health. Medical interventions should only be carried out as necessary for therapeutic purposes with the involvement of the child and their guardian in all decisions on their right to health.
- Prohibit the use of seclusion, physical restraints, and isolation as a means of managing or disciplining children in care, as a measure of adaptation to the institution, or as convenience for staff.
- In the case of adults, require that all medical treatment is undertaken only with free and informed consent of the person receiving the treatment. Provide persons with disabilities with the support they might need to exercise their right to free and informed consent to medical treatment. Any forced medical intervention should be strictly limited to emergency situations when a person's life is exposed to imminent threat or a condition of similar gravity and should be used only as a last resort in the same manner on any adult with a life threatening condition who is unable to consent to treatment at that moment, lasting only until the condition has subsided.
- Ensure reproductive health care services provided to women with disabilities, including medical interventions, are based on the free and informed consent of the person concerned, not their guardian. Provide women with disabilities with the support they might need to exercise their right to free and informed consent to medical intervention.
- Establish training requirements for child welfare workers, including institution staff, and foster parents to promote more effective advocacy for children in their custody regarding health care, psychiatric medications, and monitoring.

- Implement the recommendations of the UN Committee on the Rights of Persons with Disabilities from April 2016, with particular attention to the recommendations on protecting children with disabilities in all institutional settings from violence, abuse and ill-treatment of any kind, and on prohibiting medical treatment without prior informed consent.

Move children and adults with disabilities from institutions to communities, through the following measures:

- Develop a concrete action plan for deinstitutionalization of children and adults with disabilities. Ensure that children, young people, and adults with disabilities, their families, disabled persons organizations, NGOs, and the Ombudsperson are invited to participate in the formation of this plan.
- Develop individual plans for each person's exit from the welfare system, including a plan on community-based support and services.
- Establish a coordination mechanism between actors in health, education, social and family welfare, and finance to share information and strategies in national deinstitutionalization efforts.
- Adopt a policy decision ensuring that the Ministry of Labour, Employment, Veteran and Social Policy will not support, including through funding, the construction of new institutions or major work for existing institutions for the purpose of perpetuating institutionalization. The cost of essential repairs for existing institutions should be included in the operating budget of each institution.
- Prioritize a family's right to raise their children and the principle that children are usually best raised in their families. Prohibit separation of children from birth families because of poverty and financial reasons.
- Support and strengthen birth families of children currently placed in institutions or foster care with the aim of reuniting the child with her or his birth family.
- Establish and maintain a range of community-based services and support for individuals with disabilities, including children and their families, including rehabilitation services, educational, and vocational services, and income support for families.

- Address the needs of children with disabilities and their families in order to prevent the need for institutionalization; involve them in the planning of community-based services and support; invest in specialist care and income assistance programs so that families can afford to look after their children; make transportation and respite care accessible and affordable.
- Allocate sufficient resources for the development and sustainability of a range of services and support for children with disabilities and their families. The services and support need to take into account those children who require intensive support or may be at risk of remaining in institutions indefinitely. Ensure children with disabilities, their families, and disabled persons organizations are included in the development of services.
- Recognize and support family outreach service for children with disabilities and their families. Ensure adequate and appropriate funding for this service to ensure its sustainability.
- Institute a support benefit for children who require intensive support – such as 24-hour personal care – to enable a parent to work. Recognize that a parent who stays home and provides care for a child that requires intensive support as a caregiver of the child.
- Allocate the necessary funding for community-based services and support rather than institutional placement and services.
- Make information about community services and support available to children with different kind of disabilities and their families.
- Reform the Law on Social Protection to require the Centers for Social Welfare to make reasonable efforts to prevent separation from families, including through consistent provision of information and education of parents about their rights, their child's rights, the community-based services available to them and options other than institutions. Such information and education should be provided both at birthing hospitals, as well as continuously throughout childhood.
- Ensure periodic review of the placement of children in institutions or foster care.

- Implement the recommendations of the UN Committee on the Rights of Persons with Disabilities from April 2016 pertaining to deinstitutionalization and support services in the community.

Ensure all children and young people with disabilities enjoy their right to an inclusive, quality education, on an equal basis with others, in line with article 24 of the CRPD:

- Implement the provisions of the Law on Fundamentals of Education on inclusive education at all levels of the education in such a way as to achieve maximum inclusion of children with disabilities in mainstream schools and to avoid exclusion, including the segregation of children with disabilities in separate classrooms.
- Ensure reasonable accommodation for people with disabilities in public schools so that they can exercise their right to education.
- Collect and regularly publish information on children with disabilities included in mainstream schools, special schools, and out-of-school, in order to provide an accurate account of the status of enrollments. This should include children with disabilities who live with their families, in family like settings, and in institutions.
- Hold accountable officials responsible for education, state institutions for people with disabilities, and legal guardians for progress made toward guaranteeing all children with disabilities, including those living in state institutions, access to inclusive education.
- Implement recommendations from the UN Committee on the Rights of Persons with Disabilities from April 2016, on inclusive education, with a particular emphasis to the recommendation on giving special attention to children with multiple disabilities and children with disabilities living in institutions.

Protect the right to legal capacity and supported decision-making for persons with disabilities, in conformity with Article 12 of the Convention, through the following measures:

- Reform the Family Law on legal capacity to create a system in which persons with disabilities are supported in making decisions rather than deprived of the ability to exercise their rights. Involve persons with disabilities, particularly those affected

by deprivation of legal capacity, in the process of developing legal capacity reforms.

- Abolish full guardianship and establish a deadline for review of all court decisions on deprivation of legal capacity.
- Reform all other laws that deny persons with disabilities the right to legal capacity, including the social welfare law that permits placement of an adult in institutions without consent.
- Implement the recommendations on the right to legal capacity and supported decision-making of the UN Committee on the Rights of Persons with Disabilities from April 2016.

To the European Union

- As part of future accession negotiations with the Serbian government and other EU candidate countries, ensure that the rights enumerated in the CRPD are part of the accession requirements (acquis) and integrated into negotiations on the chapters on Judiciary and Fundamental Rights, Employment and Social Welfare, and Consumer and Health Protection.
- Create direct links between the in-country delegation and local NGOs and disabled persons organizations that provide community-based support services for children with disabilities and their families. Include the viewpoints of these NGOs in the European Commission's assessment of Serbia's progress on deinstitutionalization.

To Serbia's International Partners

- Serbia's international partners, including the European Union and its member states, UNICEF, the World Bank, and other international financial institutions and all donors – governmental and nongovernmental – engaged in assistance programs with Serbia in the context of multilateral and bilateral funding should:
 - Raise the concerns detailed in this report about the plight of institutionalized children with disabilities on the occasion of bilateral and multilateral dialogues with Serbia and proactively look for opportunities to advance the recommendations formulated to address them;

- Earmark financial and other forms of support and assistance toward support services for families of children with disabilities and prevention of institutionalization of children, as well as towards family reunification and other forms of family-based care for children with disabilities separated from their biological families;
 - Ensure that projects receiving funding for initiatives such as prevention of child institutionalization, family reunification of institutionalized children, and protection of the rights of children living in institutions, explicitly include children with disabilities;
- Continuously monitor all community-based projects providing services and infrastructure for children such as schools, recreational programs, and health care to ensure that all parties implementing such projects (i.e. contractors, construction workers, program managers, and other parties) incorporate the needs of children with disabilities for accessible services and infrastructure.

Acknowledgments

This report was researched and written by Emina Ćerimović, researcher in the Disability Rights Division of Human Rights Watch. Jane Buchanan, associate Europe and Central Asia director, participated in the field research.

The report was edited by Shantha Rau Barriga, director of the Disability Rights Division, Jane Buchanan, associate Europe and Central Asia director, and Danielle Haas, senior editor at Human Rights Watch. Lydia Gall, Europe and Central Asia researcher; Elin Martinez, children's rights researcher; Hillary Margolis, women's rights researcher and Diederik Lohman, associate director for health and human rights, provided expert reviews. Senior legal advisor Aisling Reidy provided legal review and Babatunde Olugboji, deputy program director, provided program review. Sakae Ishikawa, senior video editor, and Connor Seitchik, multimedia associate, directed and produced the multimedia component of this project. Meg Mszyco, disability rights associate, provided editorial assistance. Olivia Hunter, publications associate; Jose Martinez, administrative coordinator, and Fitzroy Hepkins, administrative manager, provided production assistance.

Human Rights Watch hereby expresses its appreciation to a number of nongovernmental organizations, disabilities rights advocates and others in Serbia, including VelikiMali, the National Mental Health Organization (MNRO), the Network of Children in Serbia, the Centre for the Rights of the Child, Mental Disability Rights International, Grig Centre, Ideas, UNICEF Representative to Serbia, Delegation of the European Union to Serbia, the Commissioner of Equality and the Ombudsman Office - for assisting us, in various ways, with our research. We thank the Ministry of Labor, Employment, Veteran and Social Policy for giving us permission to visit the institutions and small group homes; the Centers for Foster Placement for facilitating meetings with foster families; and Zvečanska Center for Protection of Infants, Children, and Youth for putting us in touch with some birth families.

Human Rights Watch appreciates the valuable input and preliminary research of Kim Samuel which acted as a catalyst for this report.

Finally, Human Rights Watch thanks all of the children and young people with disabilities, and their parents who shared their experiences with us; we recognize their courage and dignity about their personal histories and concerns.

Appendices

Appendix 1: Correspondence with the Ministry of Education

1. Letter from HRW 1.a
2. Letter from Ministry 1.b ²⁷³
3. Letter from Ministry 1.c

Appendix 2: Correspondence with Ministry of Health

1. Letter from HRW 2.a
2. Letter from Ministry 2.b²⁷⁴

Appendix 3: Letter to the Ministry of Labour, Employment, Veteran and Social Policy

1. Letter from HRW 3.a

²⁷³ Unofficial translation for Human Rights Watch.

²⁷⁴ Unofficial translation for Human Rights Watch.