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²⁷³ Unofficial translation for Human Rights Watch.

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Appendix 1 : Letter from HRW

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April 19, 2016

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Dear Mr. Nedović,

We are writing to thank your ministry for meeting with us in December 2015 with regard to our research on access to education for children with developmental and intellectual disabilities in Serbia and to request further information from your Ministry in relation to our findings.

In December, we had a productive meeting with Ms. Gordana Cvetković, Head of the Office for Social Inclusion at the Ministry of Education, Ms. Liljana Simić, Associate for Inclusive Education at the Ministry of Education, and Ms. Snežana Juković, Adviser for Social Inclusion at the Ministry of Education. We greatly appreciate the information they provided regarding access to education for children and young people with disabilities in Serbia. We welcome the constructive dialogue between the Ministry of Education and Human Rights Watch.

Human Rights Watch is an independent nongovernmental organization dedicated to defending and protecting human rights, working on more than 90 countries around the world.

Between October and November 2015, Human Rights Watch researchers carried out 118 interviews with children and young people with disabilities, their families, foster care families, civil society organizations, legal experts, UNICEF, the Serbian Ombudsperson, the Commissioner for Equality, and government officials. The research included visits to five large social welfare homes and three small group homes for children and young people with disabilities in Belgrade, Niš, and Aleksinac.

Based on our interviews with the abovementioned groups as well as analysis of Serbian government policies and laws, we have identified a number of concerns that we would like to share with you. We would welcome any information on the Ministry of Education's efforts to ensure that children and young people with disabilities enjoy their rights, so that we can reflect this information and the perspectives from the Ministry of Education in our research. We have also written to other ministries regarding concerns that relate directly to issues within their competencies.

Human Rights Watch would appreciate your response to the following concerns:

1. Access to education for children with developmental and intellectual disabilities who live in the community

Human Rights Watch is concerned that our research indicates that large numbers of children with developmental and intellectual disabilities do not have access to mainstream education and are either out of school altogether or in segregated special schools or classrooms exclusively for children with disabilities.

UNICEF, local disability and child's rights experts, and family outreach workers, told Human Rights Watch that, despite the national law that protects the right to free, inclusive, and compulsory primary education, many schools in Serbia refuse to admit children with disabilities on the basis that they have no means to educate them.

Instead, Human Rights Watch found that school-aged children with disabilities who live with their families or foster families spend the majority of their time in day care centers (so called "living rooms") or at home.

For children with disabilities who are included in the education system, Human Rights Watch found that the majority of those documented attend special schools or special classes within mainstream schools that are exclusively for children with disabilities. For example, all children who live in small group homes in Belgrade and Aleksinac attend special schools for only children with disabilities.

2. Access to education for children with disabilities who live in social welfare institutions

Human Rights Watch is also concerned about the lack of access to education for children with disabilities who live in social welfare institutions. For example, out of 167 children who live in Kolevka Institution, only 23 go to school. None of the 22 children and 69 young people who live in Stamnica Home for Children and Adults with Disabilities attend school.

Similarly to children with disabilities who live in the community, the few children who live in institutions and receive education attend specialized schools or classrooms exclusively for children with disabilities. Some are also educated within the institution. We are concerned about the quality of this education and the segregation from their peers.

We also documented that children who might be formally included in the education system do not attend school on a regular basis. For example, Human Rights Watch researchers visited all institutions during school hours and found a large number of school-aged children in the institution. The institution staff often claimed that the children's health was too fragile for them to be in school.

We found that many children are excluded from school because they did not start early enough. For example, at Kolevka Institution, a staff member explained that many children between the age of 13 and 15 do not go to school because they are "now beyond the age to enter school."

Human Rights Watch learned that for young people with disabilities, secondary education is not widely available, and where it is available, is limited to vocational training.

We would greatly appreciate information about the Ministry of Education's efforts with regards to these concerns and what steps, if any, it intends to take to address them. Particularly, we kindly request your responses to the following questions:

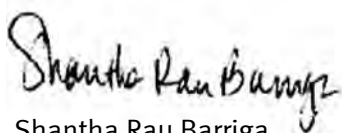
- How many school-aged children (6-15 years of age) with developmental and intellectual disabilities live in Serbia with their families or foster families? What percentage of them are out of school? Out of this number, how many children attend special schools or classrooms for only children with disabilities? How many children receive education at home?
- How many adolescents (15-17 years of age) with developmental and intellectual disabilities live in Serbia with their families or foster families? What percentage of them are included in school? Out of this number, how many teenagers attend special schools or classrooms exclusively for children with disabilities?
- How many young people (18-26 years of age) with development and intellectual disabilities live independently or with their families or foster families in Serbia? What percentage of them are included in schools or universities? Out of this number, how many young people attend special schools or classrooms exclusively for persons with disabilities?
- How many school-aged (6-15 years of age) with developmental and intellectual disabilities live in Serbian institutions for social welfare, including small group homes? What percentage of them are out of school? Out of this number, how many children attend special schools or classrooms for only children with disabilities? How many children receive education within the institution?
- How many adolescents (15-17 years of age) with developmental and intellectual disabilities live in Serbian institutions for social welfare, including small group homes? What percentage of them are out of school? Out of this number, how many children attend special schools or classrooms for only children with disabilities? How many teenager children receive education within the institution?
- How many young people (18-26 years of age) with development and intellectual disabilities live in Serbian institutions for social welfare, including small group homes? What percentage of them are included in schools or universities? Out of this number, how many young people attend special schools or classrooms exclusively for persons with disabilities?
- How many mainstream schools offer inclusive education to children (6-15 years of age), adolescents (15-17 years of age) and young people (18-26 years of age) with developmental and intellectual disabilities? Do some mainstream schools offer inclusive education only to some children and young people with disabilities?

- What concrete measures has the ministry taken to enroll in the education system children and young people who are currently out of school?
- What practical measures has the ministry taken to ensure that all children with disabilities have access to mainstream schools?
- What practical measures has the ministry taken to ensure that young people with disabilities have access to mainstream schools and universities?
- What specific steps has the ministry taken to ensure that children and young people with disabilities living in institutions and small group homes have access to inclusive education in their communities?
- What measures has the government of Serbia taken to develop inclusive education at all levels in such a way so as to achieve the maximum inclusion of children and young people with disabilities in mainstream schools and to avoid exclusion, including the segregation of children with disabilities in separate classrooms?
- What steps have been taken to ensure reasonable accommodations to allow children and adults with disabilities to ensure their right to education?
- What steps has the government taken to ensure officials responsible for education and state institutions for children with disabilities are accountable for progress made toward guaranteeing all children with disabilities, including those living in state institutions, access to inclusive education?
- Can you provide us with any information regarding efforts your Ministry has taken to collaborate with the Ministry of Health and the Ministry of Social Policy to ensure access to equitable and inclusive education for children with disabilities in Serbia?

We would be grateful to receive your reply by May 2, 2016. If received by this date your response will be reflected in our published material. Your office should not hesitate to respond to our researcher, Emina Ćerimović, via email at cerimoe@hrw.org, fax at +1 212 377 9455 or post at 350 5th Ave, 34th floor, New York, NY, 10018, USA. You are welcome to send your reply in Serbian or English.

We look forward to learning your perspectives on the situation of children with disabilities in Serbia and working with you to ensure their full rights.

Yours sincerely,



Shantha Rau Barriga
Director
Disability Rights Division

To: Human Rights Watch

Dear,

Before we provide answers to your questions, please allow us to remind you once again that since 2009, inclusive education has been defined as a strategic commitment and legal obligation of the educational system in the Republic of Serbia. Inclusive education in practice means high quality education for all, because it allows for the participation in the education and upbringing processes for all children, and it also allows them to become independent, to study, to be integrated into their peer groups, and to make progress. Serbia has recognized the significance of inclusive education as the best way to exercise the rights of each child. The Law on the Basics of the Education and Upbringing System (ZOSOV), at all levels of pre-university education, guarantees all children the access or the right to education, and to attend school that includes supplementary support and an individual approach provided by the school or pre-school institutions.

The development of inclusive education has been supported through the establishment of new structures at the national, local, and school levels, including employee training, supplementary funding directed to the development of institutions, improvement of support networks, strengthening of parents, public campaigns, and promotion and printing of materials for employees and parents. Significant resources have been invested into informing and sensitizing all those involved in the support to development, the educational system, and child care.

In line with the 2020 Educational System Development Strategy, the Law on Basics of the Education and Upbringing System (Official Bulletin of the RS, Nos. 72/2009, 52/2011, and 55/2013, 35/2015) defines the main principles and tools for attainment of education: introduction and affirmation of the inclusive approach; equal opportunities for all children; anti-discrimination, desegregation, tolerance; the best interest of the child; enrollment of all children, an individually tailored approach and individual education plan (IOP), Expert Teams for Inclusive Education and Teams for Support to Individual Children at Schools and Pre-School Institutions, pedagogical assistants, involvement of parents in the planning, implementation, and valuation of the individual support plan (IOP), and cooperation within the local community.

The education system must ensure equal rights for all children, students, and adults in access to education without discrimination based on gender, social status, cultural or ethnical affiliation, religious differences, place of residence, financial or health conditions, or disability - that is to say, based on difficulties in physical or mental development. Article 10 of the Law on Basics of the Education and Upbringing System defines as follows – a child with a disability shall be educated at the primary school jointly with the other children. When it is in the best interest of the child, he or she may be enrolled into a school for special education when this is in line with the Law. A child with a disability is entitled to an IOP in line with the law, and according to Article 69, a child with a disability is entitled to free transport regardless of the distance between the place of residence and the school.

Enrollment of All Children of Age into the First Grade.

Each child who, prior to the beginning of the school year, is between 6.5 and 7.5 years of age shall be enrolled in the first grade. A child older than 7.5 years may be enrolled in the first or another appropriate grade on the basis of a prior knowledge test if due to illness or for other reasons he or she has not been enrolled in the first grade in due time. Every child must be enrolled in school, regardless of whether he or she has been late for enrollment. The children late for enrollment shall be enrolled on the basis of the statement provided by their parents or guardians; the documents for enrollment are compiled and the medical examination and testing are done subsequently.

The school is required to enroll each child from the geographical area covered by the school. The school may also enroll a child from the geographical area of another school, upon the request of parents and in line with its capacities. In exceptional cases, children from vulnerable social groups may be enrolled in school without the proof of residence for parents or the necessary documentation. Instead of checking for preparedness for school, the testing is only conducted after the enrollment of the child into school, in order to determine whether the child needs supplementary support in order to achieve improved results during regular schooling. The testing also should be conducted in the native language of the child, meaning that in case the child cannot speak Serbian (or can speak it less than perfectly), the testing with the child may also be attended by a person (interpreter, pedagogical assistant, representative of a non-governmental organization, the parent or someone else) who will ensure that the child understands all of the questions asked, as well as that all his/her answers have been correctly translated. The testing of children with motoric and sensory disorders shall be conducted in application of the form of examination to which the child can provide optimum response. Foreign nationals and stateless persons shall exercise the right to education under the same conditions as the nationals of Serbia.

The adopted antidiscrimination enrollment and curriculum policy also includes the bylaws as follows: the Book of Rules on Detailed Instructions and Rights to IOP, Its Implementation and Evaluation: the Book of Rules on Supplementary Educational, Medical and Social Welfare Support for Children and Pupils.

Various mechanisms have been developed for securing additional support to children and pupils in the education and upbringing process, as well as in participation in community life. At the level of all pre-school institutions - primary and secondary schools - Expert Teams for Inclusive Education (STIO) have been formed, and have been tasked to work on the development and improvement of the inclusive environment, policy, and practice at the institutional level. The STIO designs the measures for the implementation of inclusive education at school and the mechanisms for complete inclusion of children, application of antidiscrimination measures, as well as for development of teachers' competencies for IE. The Team has been working on timely identification of children from vulnerable groups, encouraging the participation of parents, and overseeing the cooperation between teachers and parents in the process of creating support to children.

The development and progress of all children is monitored on a regular basis. The first level of support to children not attaining the expected performance in education is offered through differentiation and individual tailoring of curricular and extracurricular activities. If the

support provided through individual tailoring fails to bring about a positive shift in the child's performance (as a rule, during the first quarter), then the development of an individual education plan with adapted program is proposed (IOP 1 – adaptation of methods, materials, space, conditions) according to which the education and upbringing process shall be conducted for such child/pupil. The Expert Team for Inclusive Education provides the proposal for development of the individual education plan, and it is to be drafted by the team for provision of support to the child/pupil, consisting of the teacher/pedagogue, the parents/guardians of the child, and an expert associate. If the support measures envisaged in the IOP-1 document fail, with the approval of parents and with the opinion of the ISC, the Team for Provision of Support to the Child proceeds to develop the IOP-2 document, which involves amending/reducing the contents, outcomes, and standards. For gifted children, IOP-3 is drafted with expanded contents, outcomes, and standards.

The emphasis is placed on abandoning the model focusing on what children do not know and cannot do in favor of the approach directed towards strengths, focusing on knowledge and skills that children possess. When designing activities, the baseline is in the previous experiences and competences of children in order to support their further development and learning. Some of the strategies that have proven effective in practice in terms of managing a class/group for education of children needing supplementary support in education are: differentiation of curricula/activities (contents, instructions, activities, products), use of multi-communication channels, working in small groups, cooperative teaching and team work, flexible group rules, peer tutoring, and peer learning.

Children from vulnerable groups also receive support when going through final examinations. On the basis of the support needed, children are entitled to: passing of examinations under special conditions, adapting the existing tests to the specific needs of the child, or developing of special tests in line with the amended education standards.

Children from vulnerable groups also receive support for enrollment into secondary schools. Children are provided with support through professional orientation and referrals for pupils to adequate secondary schools by the district commission for enrollment. At enrollment into secondary schools and colleges, Affirmative Actions are implemented for the pupils coming from the Roma ethnic minority group (under the auspices of the Office for Human and Minority Rights and the National Council for the Roma Ethnic Minority of Serbia).

The provision of high quality and efficient support to the child/pupil involves the coordination and implementation of various actors. The institutions with developed inclusive practice are characterized by openness, cooperation, and team work within the institution; the school/pre-school documents are applied in a flexible way; the institutions are ready to modify the schedule of classes in order to allow for the merging of classes and teamwork by teachers, allowing for a flexible pace of day at pre-school institutions, organizing needs-based online supplementary/additional lessons, and facilitating peer assistance on the way from home to school, etc.

Special attention is given to the educational inclusion of the ethnic Roma children through various projects, which are also integrated into systemic solutions. Today, 179 pedagogical

assistants function within the educational system, who are tasked to offer assistance and supplementary support to children and pupils and assistance to teachers, pedagogues and expert associates in order to improve their work with children and pupils who need supplementary educational support. In their work, they cooperate with parents or guardians, and jointly with school principals. They also cooperate with the competent institutions, organizations, associations, and local self-administration units. Hiring of pedagogic assistants has significantly facilitated the inclusive education of Roma children, and this would have been harder without the support of (Roma) pedagogical assistants, so they constitute one of the central pillars in the social inclusion of the Roma ethnic community in Serbia. Their contribution is reflected in the increased access to education, in the prevention and reduced abandonment of the education system, in stimulating balanced quality in education for all children, in improved school success and performance for children, and in more efficient implementation of anti-discrimination and anti-segregation measures. The support for educational inclusion of the ethnic Roma children includes affirmative campaigns for enrollment into secondary schools and colleges, provision of mentorship to pupils, as well as of scholarships, etc. The problems need to be addressed systemically and on a long-term basis: the children from the Roma community have been facing numerous hardships in the exercise of their rights to enjoy high quality education: the Roma children are far less involved in pre-school education programs, and they are not even fully covered by the mandatory pre-school preparation program (PPP) or if they are, they attend it irregularly and for a short duration of time; a large number of children have not sufficiently mastered the language they are educated in; there is a lower coverage and lower rate of graduation in the primary and secondary education; there is insufficient support for learning of the Roma language and for the development of cultural identity within mandatory education; there is only minimal coverage for higher education; the issues of segregation, systemic poverty, an insufficient number of pedagogical assistants in relation to the need, as well as too few teachers and pedagogues who are ethnic Roma.

In recent years, pedagogical assistants (PA) have worked exclusively with ethnic Roma children. The law has created the option whereby pedagogical assistants can also work with children coming from other vulnerable groups, which pertains to the children living in deprived environments and socio-economically unfavorable situations, or children who come from displaced or deported families. There is a plan currently to develop a new Book of Rules on Pedagogical Assistance, and to govern the requirements and criteria for their hiring with more precision.

The support measures envisaged as support for children constitutes involvement of a companion for personal assistance to the child for the purpose of easier functioning and communication with others during the educational and upbringing work at pre-school institutions or during the educational and upbringing work at schools; during the full day classes or extended care, extracurricular activities, or such classes in nature, outings, excursions, and vacations. This service falls into the services from the domain of social protection, thereby meeting the rights of the beneficiaries to ensure their living in a natural environment, optimum development of their potential and integration into their social environment. The establishment, development and provision of the service involving the

personal companion of the child is in the domain of the local self-administration units. Under the project titled “Personal Companion of the Child – Support to the Child in Growing Up” funded by the Belgrade City Administration – Secretariat for Social Protection, in cooperation with aid organization “Child’s Heart (Dečje srce)”, 250 children from the territory of Belgrade City received the service involving *Personal Companion of the Child*. The persons hired to provide the services of the child’s personal companion have been trained for the provision of this service based on the program accredited by the Republic Institute for Social Protection. The provision of the service includes taking and bringing back children from home to school, as well as spending time with the child at school or kindergarten in order to provide assistance in daily activities. Unfortunately, the need for this service is much higher; 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.

The Ministry of Education, Science and Technical Development (MOESTD) and the UNICEF Office for Serbia have supported the project titled “Info-Line for Parents – Support for Inclusive Education”, as implemented by the organization *VelikiMali Inclusion Initiative (Inicijativa za inkluziju VelikiMali)*. The introduction of the info-line is to contribute to increased and improved involvement of parents in the educational and upbringing process and towards the development of inclusive education, because the results of the monitoring and evaluation of inclusive education have indicated that parents have been insufficiently informed and that they need support in interpreting laws and bylaws in the process aimed at exercising the right to education for their children. The info-line (phone number 0800100121) is active on work days from 12:00 to 19:00 hours.

The parents’ telephone calls are answered by experts from the *VelikiMali Inclusion Initiative*, who are in communication on an as needed basis with the members of the Social Inclusion Group within the MOESTD, providing information on:

- Laws and bylaws that support inclusive education and social inclusion;
- Measures and activities to ensure high quality education and upbringing of children/pupils;
- Supplementary support measures for children/pupils and the families, and the methods for their implementation;
- Useful reference materials on inclusive education and good practice examples.

In the period from January 11 through February 29, the info-line received 76 calls from families and they either received information directly or were referred to other institutions while receiving additional information via e-mail. 95.7% parents/callers stated that they were very satisfied with the quality of the services, advice, and information.

Through the analysis of records, the organization *VelikiMali Inclusion Initiative* will obtain data for further planning of support to parents and development of strategy for timely and high quality information for all involved in education and upbringing.

The most frequent questions pertained to personal companion service, pedagogical assistance, enrollment into the primary school (regular or special school), procedures for

deferred starting of school education, the meaning of supplementary support in education, transfers from special to regular schools, final examinations for the pupils receiving education as per the IOP and the method of adaptation, opportunities for continuation of education after the completed special primary school, enrollment into secondary school for pupils with disabilities or developmental disorders, provision of adapted didactical materials, appeals against procedures at other institutions, transfer onto the subject-based teaching for children receiving education as per IOP, adult education, why there is no defectologist support at regular schools, opportunities in education for children with serious health difficulties and developmental disorders, how to proceed when a private secondary school refuses to enroll a dyslectic child and attempting to justify this by explaining that they are not being trained to work with such pupils, expert treatments at kindergartens for children with developmental disorders, how to reduce resistance against inclusion at schools, how to strengthen schools in order to experience parents as partners, enrollment into education of gifted children, explanation of the info-line services, etc. The answers to the most frequently asked questions will be published on the website of the Ministry of Education, Science and Technological Development on the official page of the Group for Social Inclusion. All information received from beneficiaries via the info-line are kept pursuant to the Law on Protection of Personal Data.

The DILS project, implemented until 2014 with the World Bank, created the preconditions for enforcement of the legal provisions on supplementary services at the local level: grants for 56 local self-administration units for implementation of the educational inclusion of Roma, 281 grants for schools – Support for Inclusive Education, 9 grants from partner schools – and development of a functional inclusive education model. The grants were allocated to the schools involved in the inclusion process: 9 pilot schools for testing of functional IE models, 25 pilot institutions for testing of grant schemes and training, and 281 schools supported by improving school capacities for successful inclusion and enabling of high quality education for children from deprived environments and vulnerable social groups. Under the DILS project, 21 vehicles were procured for transportation of children with disabilities and were handed over for use to the local self-administration units. Also, the training courses improved competences for 17,000 persons at educational institutions and for 900 participants working with disabled children. It improved the sensibility of all school stakeholders and the local community for acceptance of and support to children/pupils with disabilities. Special attention was attached to improving the cooperation with parents and children with disabilities, and with the relevant institutions and organizations at the local level.

In cooperation with UNICEF, the MOESTD formed the national IE Support Network (80 experts). Also, the Ministry and schools took part in the project titled Regional Support to IE, implemented by the Council of Europe and funded by the European Commission.

Over the recent years, career guidance has been introduced in primary education in the Republic of Serbia. The career guidance and counseling strategy was adopted in 2010, and the Ministry of Education, Science and Technological Development and the Ministry of Youth and Sports initiated a program involving professional orientation for the pupils of the seventh and eighth grades at schools, covering 90,000 pupils. In the past, lacking this support, the pupils were mainly left to decide themselves on their future profession on the basis of the suggestions from parents, relatives or peers. The Law on Primary Education and Upbringing

and Law on Secondary Education and Upbringing include professional orientation (Law on Primary Education and Upbringing, Article 43) and career guidance (Law on Secondary Education and Upbringing, Article 15) as part of the school program led by the school's professional orientation team. Professional orientation and career guidance have been envisaged as a regular activity for school-based psychologists and pedagogues (Rulebook on the Program of All Forms of Work for Expert Associates, 2012), they have been trained for it and have been implementing it for years. The affirmative policy measure has also been introduced for enrollment of students with disabilities into higher education, parallel with affirmative measures for placement into student dormitories.

As for textbooks, Article 4 of the new Law on Textbooks (Official Bulletin No. 68/2015) prescribes that pupils with disabilities should use the textbooks with format/script adapted to their needs. Article 5 defines the teaching aids as teaching tools used in the education and upbringing work with disabled children.

The Government of the Republic of Serbia has adopted the Rulebook on Internal Regulation and Systematization of Work Posts at the Ministry of Education, Science and Technological Development, No. 110-00-9/2015-02, establishing the organizational unit called the Group for Social Inclusion, which is tasked to facilitate the development of inclusive policy and undertake the measures necessary for strengthening the institutional framework.

In October 2015, the Ministry of Education, Science and Technological Development started an initiative for a re-establishment of the Joint Body for support in work and for coordination of supervision over the work of Intersectoral Commissions (ISC) in order to assess the needs for provision of supplementary educational, health care and social welfare support to children and pupils (hereinafter referred to as the Joint Body).

At the time, letters were sent out to the Ministry of Health, Ministry of Labor, Employment, Veteran and Social Welfare Affairs, as well as to the Ministry for State Administration and Local Self-Administration. All of the Ministries delegated their representatives for the Joint Body at the level of state secretaries, and on December 30, 2015 the preparatory meeting was held at which it was decided that the appointees for the members of the Joint Body should also include the representatives of the Office for Human and Minority Rights, Team for Social Inclusion and Poverty Reductions, Standing Conference of Cities and Municipalities, UNICEF, Republic Institute for Social Protection, as well as the representatives of four CSOs active in the field of inclusive education. The novelty in the work of the Joint Body is the involvement of the Ministry for State Administration and Local Self-Administration, due to the need to establish functional procedures and mechanisms in order to provide supplementary support at the level of local self-administration units.

On January 14, 2016, jointly with the Office for Cooperation with the Civil Society of the Government of the Republic of Serbia, a public call was issued for the CSO representatives in the Joint Body (the call was repeated in February, because not a single parent association had applied).

The Proposed Law Amending the ZOSOV is in due procedure, and in part it pertains to the work of the Intersectoral Commissions. Upon its adoption, it has been planned that the first

session of the Joint Body would discuss the draft amendments to the Rulebook on Supplementary Educational, Health Care and Social Welfare Support to Children and Pupils. The draft Rulebook has been prepared and, among other things, it will regulate how the data on children is to be compiled, and how the data would be handled and protected.

In order to enhance the work of the ISC, under the project titled *Enhancement of Professional Community Support – an Important Step in Child Inclusion*, implemented by the Social Welfare Policy Center in cooperation with the Ministry of Education, Science and Technological Development, UNICEF, Standing Conference of Cities and Municipalities, and the Team for Social Inclusion and Poverty Reduction, training courses have been organized for all municipal coordinators and ISC members from all of the three systems. The training courses have been attended by 449 ISC members from 123 municipalities, and they discussed all relevant issues on the work of the ISC, ranging from procedures, actions, meeting of deadlines, reporting and funding, and recommendations have been given for the improvement of the ISC work. Through this project, other data has also been compiled on the work of the ISCs which have been established at 153 municipalities. This data will be presented to the Joint Body and will be the starting point for further enhancement of the ISC work. Under the same project, there has been an increased effort in working with 10 ISCs in the municipalities of Leskovac, Bojnik, Vladicin Han, Bela Palanka, Pirot, Kragujevac, Pancevo, Kovin, Smederevo, and Pozarevac. In addition to the training courses and mentoring work with the ISC members, these municipalities have also received grant funds for supplementary support to children who possess the opinions from the ISC. The ISC members from these municipalities have also passed several days of training under the project, and this training program has also been implemented with 17 ISCs from all of the Belgrade municipalities.

A program for the ISC work database has also been developed, which should be the basis for monitoring of the ISC work. The application of this program is linked to the adoption of the Law Amending the ZOSOV. We expect that through the work of the Joint Body some other issues related to the ISC work will also be addressed, in particular those related to development and funding of integrated local community services in order to ensure support for all children and pupils who need supplementary educational, health care and social welfare support.

A note in relation to the statements in your letter requesting the MOESTD to supply information on the support received by children/pupils from vulnerable population groups – it is important for us to stress that at the national level, mechanisms have been systemically envisaged, legally supported, and operationally developed which enable all children to have access and support within the education and upbringing system.

We are aware that the quality of the support provided is still uneven, **but the MOESTD has no information about any schools having refused to enroll children/pupils with developmental disorders or disabilities or any other children or pupils from vulnerable population groups.** Resistance has arisen in a small number of cases, but mechanisms have been developed and applied in order to address those sporadic situations. This includes the involvement of education inspectors, advisors from the competent school administrations, Inclusive Education Support Network or, as needed, members of the Group for Social Inclusion under the MOESTD. We have no information about whether due to the resistance

from the school there has been any children who have remained non-enrolled into regular education. You have requested a lot of data that the Ministry of Education, Science and Technological Development does not have available, because in fact they are not within its scope of competence, such as: the number of children living in families, in foster families, in small public home communities; and, in relation to these parameters, how many of them attend which schools. The MOESTD is aware of the need to enhance the mapping of children who need inclusion, as well as supplementary support in progress in learning and development within the education system. In those terms, the following activities have been initiated:

1. Amendments are in due course to the Law on the Basics of the Education and Upbringing System, which envisage the introduction of a single education code for each pupil, which, in addition to ensuring compliance with the Law on Protection of Personal Data, will enable more efficient recording and monitoring through the educational system for children/pupils who need support in education, and for all other children as well.
2. The MNPTR has been involved in the work of the Working Group established by the Ministry of Health, which is tasked to establish the registry of children with developmental disorders.
3. The MOESTD has initiated the development of the software for a single educational database - eCENUS.

We expect that the activities undertaken will contribute towards the records being more complete and being in the function of planning the support, monitoring of its effects and prevention of children dropout from the educational system.

Data on Children/Pupils in the Education and Upbringing System

The data available to the Ministry of Education, Science and Technological Development on the number of children from vulnerable groups attending regular schools or schools for education of children/pupils with developmental disorders do not include the information on whether they live in foster families or in their own families. This is also the information that the Ministry cannot have available in line with the Law on Protection of Personal Data.

According to the data on the 2015/2016 school year, there are a total of 580,057 pupils at primary schools. Of this number, 573,840 pupils attend regular schools, and 6,217 attend schools for education of pupils with developmental disorders, which makes up 1.07% of the total population of pupils in primary education. Of the 580,057 pupils in regular schools, 11,991 pupils from the first to the eighth grades of the primary school are educated upon the individual curriculum which is based on the adaptation of the methods and conditions under which the educational and upbringing work is conducted - IOP1 (7,616 pupils), and which is based on changed contents of the educational and upbringing work, outcomes and standards in performance - IOP2 (4,375 pupils), which makes up 2.09% of the total number of pupils in primary education (data taken from the reports of the eCENUS database maintained by the Ministry of Education, Science and Technological Development). Please note that this is not

data on the total number of children with developmental disorders and disabilities at primary schools, because for a certain number of children the adaptation has been carried out at the level of individual tailoring, and no special records are maintained to this effect.

Based on the data provided by school administrations for the 2014/15 school year, at primary schools in Serbia, there were 250 special classes attended by 1,474 pupils.

As for the coverage of children at residential institutions, the data suggests that of the 477 children aged up to 18, over 40% have been included in education. There will be an effort on having the remaining group (the case involves less than 200 children of primary school age) included in education, too. In order to attain this goal, cooperation with the Ministry of Labor, Employment, Social Welfare and Veteran Affairs will be required.

Concrete Measures Undertaken by the Ministry in Order to Include Children and Youth Currently Out of School into the Educational System

Starting as of September 2015, a campaign has been implemented to increase the coverage of children from vulnerable population groups by the preparatory pre-school program and primary education. The planning and implementation of the Campaign has involved the participation of the MOESTD, UNICEF, and professional associations such as: Federation of the Associations of Pedagogues of Serbia, Association of Expert Associates and Associates at Pre-School Institutions of Serbia, and the Collegium of Principals of Pre-School Institutions of Serbia, Association of Pedagogic Assistants of Serbia. The MOESTD – GSI has sent out written guidelines to all players with the expected/proposed activities for pre-school institutions, pedagogic assistants and Red Cross commissioners, and it has also invited the professional associations to support the inclusion of children from vulnerable groups through identification and promotion of examples of good inclusive practices at expert events. During and after the Campaign, some 1,000 children have been enrolled into pre-school institutions and primary schools.

The support to vertical and horizontal transition of children/pupils from vulnerable groups in pre-university education in the Republic of Serbia has also been carried out through compiling and presenting of examples of good practices by the school administration advisors at events involving “Joint Activities of the Group for Social Inclusion (GSI) and School Administrations (SA).” Also, the MOESTD - GSI has organized a meeting with the representatives of professional associations as follows: Federation of the Associations of Pedagogues of Serbia, Association of Expert Associates and Associates at Pre-School Institutions of Serbia, Federation of Associations of Nurses at Pre-School Institutions of Serbia, and Federation of Teachers of Serbia, and agreed that during this working year the employees at pre-school institutions (PI) and primary schools (PS) should be strengthened to provide support to children when transitioning from one to another level of education through compiling and promoting of examples of good transitional practices at expert events.

The regulations in the domain of inclusive education and social inclusion developed or enhanced during this period in order to increase the coverage of children/pupils from vulnerable groups and access to education:

- Procedure for Organization and Funding of Teaching for Pupils on Extended Home-Based or Hospital Treatment
- Proposed Procedure for Establishment of the Minister's List of Persons and List of Schools for Provision of Support in Inclusive Education
- Affirmative Measures for Enrollment of Ethnic Roma Children into Secondary Schools
- Proposed Procedure for Enrollment of Pupils into Secondary Schools Attending Classes as per IOP or Having Health Impairments
- Decision on Enrollment of Students – Affirmative Action for Enrollment of Students with Disabilities and Ethnic Roma Students
- Recommendations for Adaptation of Textbooks/Materials in Digital Format in Order to Ensure Access – published on the MOESTD website under News

Ensuring Access to Education for Children/Pupils with Developmental Disorders and Disabilities

The Ministry of Education, Science and Technical Development has created a questionnaire for the analysis of pre-school institutions and primary and secondary schools in work with children/pupils who are blind or poor of sight (the questionnaire has been responded by 1400 educational institutions; data has been compiled on 500 blind/poor of sight children and pupils) so that the Ministry would gain insight on what the needs of the schools are, what kinds of adaptations are carried out, which assistive technologies (AT) are used, and which ones are needed to obtain. Further steps go towards obtaining a number of assistive technologies for work with blind or poor of sight children/pupils listed in the questionnaire.

Under the process aimed to ensure access to education, the development of an assistive technology catalogue is under way that will be educational in character and will be available on the MOESTD website for improved information about what various kinds of assistive technologies exist. The next step is to create a web application to allow access to assistive technologies and exchange of assistive technologies among beneficiaries.

Research is also under way to determine the effectiveness and efficiency in the work of schools which have received equipment and software under the DILS program in order to enhance the teaching conditions for the pupils with developmental disorders and disabilities, as well as to lend the AT to other schools for pupils who are in need for their use.

The purpose of the evaluation is to use the data obtained as the basis for planning of future work at assistive technology resource centers, their improved networking and utilization of human and material resources.

Plans and Upcoming Activities:

The 2020 Action Plan for Inclusive Education (which is in due course of adoption) envisages the following activities:

- Enhancement of legislation in the domain of inclusive education and social inclusion: the Rulebook on the Work of ISC, Rulebook on IOP, Rulebook on Pedagogical Assistance, Rulebook on Prevention of Discrimination in the Education System, Rulebook on Model Centers, Rulebook on Records Keeping, etc.

- Preparation has been envisaged of an expert manual for enrollment of pupils from vulnerable groups into secondary schools, of instructions and recommendations for provision of support to children and pupils when transitioning from one to another education level, of instructions for keeping of records and documentation for pupils attending school based on individual curricula, as well as of instructions/decrees for allocation of specific-purpose transfers to fund the work of the ISCs and supplementary support services.
- It has been planned to start the process for further transformation of special education (schools for education of children with developmental disorders and “special” classes at regular schools) while relying on the experience derived from the best practices of the neighboring countries, as well as development of resource centers for support to inclusive education and social inclusion.
- It has also been planned to develop competences for IE through initial training of teachers and pedagogues. This includes development of the competences for IE among university professors who educate teachers, pedagogues and expert associates, and starting of an initiative for enhancement of initial education for pedagogues, teachers and expert associates through updating of existing modules and accreditation of new ones in the system of higher education for IE.
- It has also been planned to provide support to professional development of employees in education. It has been envisaged to carry out an analysis of the past training courses for pedagogues, teachers and expert associates in terms of IE, and an analysis of needs for additional training, preparation of new programs and models of professional development for pedagogues, teachers and expert associates, intended for development of transversal competences and acquisition of skills and knowledge for IE, as well as organization of training courses for employees in the field of IE, enhancement of existing and starting of innovative forms of horizontal learning and experience sharing, translation of reference materials and publication of expert and scientific works, guides, manuals and periodicals on the topic of IE and SI, and continued empowering of the employees at the MOESTD (coordinators for inclusive education at school administrations, other educational advisors and inspectors...) for activity in the field of IE.
- In order to ensure evidence-based management of the inclusive education process, it has been planned to carry out an analysis of needs among children for supplementary support, and in particular an analysis of the situation and assessment of needs among children and pupils at schools for education of children with disorders and at homes of pupils at those schools, as well as among children at residential institutions; an analysis of the effects of the affirmative measures for enrollment into secondary schools and colleges applied so far; establishment of the mechanisms for cooperation between the MOESTD and civil society organizations, aimed at providing a joint definition of policies in the IE field; all of these need to result in the drafting of a national report on the application of measures for inclusive education and social inclusion.
- The Work Plan of the Group for Social Inclusion for 2016 envisages the following activities under the component titled *Increased Access to High Quality Programs for Support to Early Development and Enhanced IE Implementation*

- Campaign for enrollment of children coming from vulnerable groups into pre-school institutions and primary schools and evaluation of effects of the campaign in terms of increased coverage of children from vulnerable population groups with preparatory pre-school program (PPP) and primary education (UNICEF, REF, Red Cross, Association of Pedagogic Assistants of Serbia - APAS, professional associations);
 - Support for application of affirmative measures for enrollment into secondary schools and colleges (school administrations, Republic-level and district-level enrollment commissions);
 - Strengthening of pre-school institutions for non-segregated education of children with developmental disorders (UNICEF, Association of Expert Associates and Associates of Pre-School Institutions of Serbia - SSSPUS, the Veliki Mali Inclusion Initiative);
 - Development of the model for transformation of special classes at regular schools (UNICEF, MOESTD);
 - Development of models and mechanisms to enhance the quality of education for children/pupils with developmental disorders and disabilities (UNICEF);
 - Strengthening of the institution for the implementation of IE, recognition and prevention of discrimination, violence and segregation, aimed at developing tolerance, appreciation of differences, respecting of human rights and increasing the participation of children/pupils/youth and parents (Group for Protection Against Violence and Discrimination; Group for Education of Minorities and Human and Minority Rights in Education, Educational and Upbringing Institutions, Pre-School Institutions, School Administrations, Inclusive Education Support Network);
-
- Support for inclusion of children from residential institutions into the educational system (MRSBP, Office for Human and Minority Rights, UNICEF, MDRI, School Administrations, Republic Institute for Social Protection);
 - Preparation and implementation of measures and activities for inclusion of migrant family children into the educational and upbringing system (UNICEF, RC, Office for Kosovo and Metohija, Commissioner for Refugees, Ministry of Interior, Ministry of Labor, Employment, Social and Veteran Affairs, Ministry of Health, Faculty of Philology).
 - Starting of initiative for establishment of a volunteering system at educational institutions. In the future, we are looking at the harmonization and completion of legislation in 3 sectors for support to IE in order to strengthen the capacities of local government levels for efficient support to IE, development of generic competences among teachers through creation and implementation of new training courses and other types of professional specialization, as well as training for principals as school leaders.
 - We are also looking at future hiring of personal assistants with the support from EU funds, and at creation of the criteria and standards for supplementary support

at institutions for education of pupils with disabilities which carry the role of resource centers.

Appendix 1: Letter from Ministry 1.c

The development of inclusive education and inclusion of an increasing number of students in need of additional support in regular classes (of regular schools) has brought about a change in the structure of students who attend special schools and special classes. In the Republic of Serbia, students with developmental disabilities (who up until recently were attaining education only in schools for children with developmental disabilities) are being increasingly included in regular classes and, on the other hand, the volume of children with multiple disabilities in schools for children with developmental disorders and disabilities is increasing.

We would like to remind you of the fact that decision-making with regard to enrollment in school of children with developmental disorders and disabilities must be preceded by acquisition of an inter-sectoral commission's opinion. In addition, enrollment in those schools is not possible without consent by the parents/guardians.

The 2016 Work Plan of the Group for Social Inclusion has envisioned that joint agency of the three systems (social protection, health care and education) provides support to inclusion of children living in residential institutions in the educational system. The Ministry of Education has already taken the first step, by addressing a memo to the Ministry of Labor, Employment, Veteran and Social Affairs, seeking precise data on children who are not included in the educational system and on representatives who will take part in the activities of the national team which will plan and monitor this process. We believe that it is necessary to establish local teams comprised of representatives of all three aforementioned systems, educational institutions, the interdepartmental commission and the residential institution which will be in charge of the enrollment, transition into the educational system, and ensuring and providing additional support to children in institutions.

With regard to awareness of the right to enrollment in school, the children's guardians are staff members at the Social Welfare Center, therefore it is implied that they are familiar with the regulations.

It is important to emphasize the fact that, according to the Law, the parent/guardian is obligated to enroll the child in school. In addition, the school is obligated to report the parent/guardian to the education supervision service in case the child does not attend school. The local self-government unit has the direct responsibility for the enrollment of all children in compulsory education.

Children over 15 attain primary education in adult education schools, according to a teaching curriculum which also entails acquiring basic professional and vocational competences. In accordance with the Law on Adult Education, primary adult education is organized into grades, from the first to the eighth grade, and lasts for a period from three to five years, as provided by the school program. The education may also be organized into cycles, whereas the duration of such cycles and the grades within such cycles is provided by the adult education program, in accordance with the law governing primary education (Article 45).

According to the data at our disposal, the total number of children with developmental disorders and disabilities who use the personal escort service amounts to 709. The total number of personal escorts engaged in the provision of this service is 612, while 581 of them provide support continually throughout the year.

According to the Regulations on the Educational Assistant Training Program ("Official Gazette of RS – Education Gazette", No. 11/2010), the 179 licensed educational assistants at the level of the Republic of Serbia have completed six compulsory modules aiming to train educational assistants for: work with the family, cooperation with outside associates, organizations and institutions, provision of support to employees at educational institutions, preparation and implementation of curricular activities, development and protection of the children.

The elective modules have aimed at training educational assistants for the provision of support and assistance to: children and students concerning language development and social skills necessary for successful education, children and students with learning disabilities, developmental and other disabilities, as well as to children and students from low-income families, rural areas and the Roma national community, while observing specific features pertaining to culture and tradition.

The Law has created the possibility for educational assistants to work, apart from Roma children, also with children/students from sensitive groups, and the training served to empower educational assistants to perform this role.

This number includes all children according to the OECD classification, who attend classes in conformity with IOP 1 (adjusted program) and IOP 2 (altered program) in regular schools.

Special classes and schools serve the purpose of educating children with developmental disorders and disabilities.

Appendix 2: Letter from HRW 2.a

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April 19, 2016

Ms. Sladjana Djukic
Assistant Minister
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Dear Ms. Djukić,

Thank you for agreeing to meet with us in November 2015 regarding the healthcare of children and young people with disabilities in Serbia. We welcome the constructive dialogue between the Ministry of Health and Human Rights Watch.

Human Rights Watch is an independent nongovernmental organization dedicated to defending and protecting human rights, working on more than 90 countries around the world.

Between October and November 2015, Human Rights Watch researchers carried out 118 interviews with children and young people with disabilities, their families, foster care families, civil society organizations, institution staff, legal experts, UNICEF, the Serbian Ombudsperson, Commissioner for Equality, and government officials. The research included visits to five large social welfare homes and three small group homes for children and young people with disabilities in Belgrade, Niš, and Aleksinac.

Based on our interviews with the abovementioned groups as well as analysis of Serbian government policies and laws, we have identified a number of concerns that we would like to share with you. We would welcome any information on the Ministry of Health's efforts to ensure that children and young people with disabilities enjoy their rights, so that we can reflect this information and perspectives from the Ministry of Health in our research. We have also written to other ministries regarding concerns that relate directly to issues within their competencies.

Human Rights Watch would appreciate your response to the following concerns:

1. Inappropriate treatment of children and young people with disabilities in institutions

Human Rights Watch is concerned that medication, including psychotropic medications, may be used inappropriately on children and young people with intellectual, developmental and psychosocial disabilities in Serbian institutions, often as a means of dealing with behavioral issues.

Staff in institutions, including medical personnel, told Human Rights Watch that the majority of children and young people with disabilities in all Serbian institutions and small group homes are prescribed psychotropic medications. In most cases, we were told that children and young people with disabilities receive the following medications: Largacitil (an antipsychotic), Rivotril (a benzodiazepine), Mendilex (an anti-cholinergic), Rissar (atypical antipsychotic), Lorazepam (a benzodiazepine), Diarpam (sedative), and Amitriptyline (antidepressant).

Human Rights Watch also consulted two child psychiatrists in the US who told Human Rights Watch that, except for Rissar, none of these medications are approved or licensed for children in the US. According to the medical information provided with the medication in Serbian, 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.

Staff in institutions, including medical staff, stated that psychotropic drugs are primarily prescribed to prevent children from harming themselves or from being aggressive to others, but also to control the behavior of children, as needed.

Staff also recognized the lack of knowledge about alternatives to support children or adults with disabilities who may be exhibiting aggressive behavior. For example, an educator in a small group home, told us, “We need more information and feedback on what to do in cases of aggression and attacks. We do have those challenges.”

Human Rights Watch also observed that children and young people with disabilities in the institutions visited had very poor dental hygiene.

2. Sexual and Reproductive Rights

Medical staff at three institutions told Human Rights Watch about invasive medical interventions they conducted on a number of young women with disabilities without their free and informed consent because they said the guardians of these women had consented to the procedures. The interventions, according to the staff, 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, anesthesia was used in every case so that the women would not resist the interventions.

3. Lack of monitoring

All five social welfare institutions where children with disabilities live that we visited had physicians and medical nurses on staff. Veternik Institution had a psychiatrist and a dentist as well. Other institutions (Kolevka, Zvecanska, Sremcica, and Stamnica) did not have a psychiatrist on staff. Medical personnel and caregivers in these institutions and small group homes told Human Rights Watch that they are allowed to administer sedatives and other psychiatric medications only as prescribed by a psychiatrist.

According to the information provided during the meeting with your ministry, Human Rights Watch was told there is no independent and periodic monitoring of medical treatment, including prescriptions, for children and young people in institutions.

4. Lack of health care for children with developmental disabilities who live in the community

Human Rights Watch is also concerned about the lack of access to adequate health care for children with developmental, intellectual, and psychosocial disabilities who live with their families or in foster care. Human Rights Watch interviewed three family outreach workers (who support children with disabilities and their families where there is a risk of separation of children), all of whom said that children with disabilities and their families face particular difficulties in accessing health care. Parents of a child with developmental disabilities told Human Rights Watch how they decided to place their newborn child with developmental disabilities in an institution because they could not access the necessary and timely health services in their community.

During the review of Serbia by the UN Committee on the Rights of Persons with Disabilities on April 5 and 6, 2016, in Geneva, Switzerland, representatives of the Serbian government reported that 70.5 percent of children with disabilities placed in institutions of social welfare are placed because of “the inability of parents to meet the health needs of the child in the community where they live.”

5. Undue pressure on and lack of information to parents

Human Rights Watch documented that parents of children with developmental and intellectual disabilities face pressure by healthcare professionals to place their children in institutions. According to institutions staff, local experts, family outreach workers and parents interviewed by Human Rights Watch, doctors and nurses in Serbia often fail to provide parents with information about their child’s health and on access to appropriate services and support groups, instead encouraging parents to place their child with disability in an institution.

We would greatly appreciate information about the Ministry of Health’s efforts with regards to these concerns and what steps, if any, it intends to take to address them. Particularly, we kindly request your responses to the following questions:

- Are there guidelines regarding the use of psychotropic medication for children?
- What procedures are put in place to ensure children with disabilities receive psychotropic medication that is licensed and approved for children in Serbia? Is there a list of approved and licensed medications for use in children? If yes, could Human Rights Watch receive a copy of the list?
- Is there any training available for health workers and institution staff regarding non-invasive ways to support children who may have behavioral problems?
- What measures have been adopted to ensure that health care services, including reproductive health care services, are based on the free and informed consent of

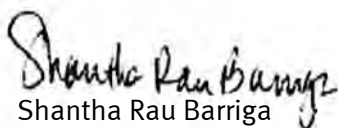
the person concerned, including children and adults persons deprived of legal capacity?

- What steps has the Ministry taken to ensure that forced medical intervention is strictly limited to emergency situations where the child's life or health is exposed to imminent danger and used only as a last resort in the same manner it would be used on any child or adult with a life threatening or equivalently serious condition who is unable to consent to treatment at that moment?
- What measures have the Ministry of Health taken to oversee the prescription of medications, including psychotropic medication, to children in institutions?
- Who gives consent to psychiatric treatment when a child is in state custody?
- What mechanisms are put in place to inform the child and the child's guardian about the potential risks and benefits of prescribed medication?
- How many women with disabilities living in Serbian institutions have undergone the following procedures without their informed consent and only the consent of the guardian, since 2009:
 1. Insertion of intrauterine device;
 2. Administration of pap smear test;
 3. Termination of pregnancy?
- What concrete steps are taken to engage women and girls with disabilities in discussions about possible medical interventions and obtain their informed consent?
- What measures have been adopted and concrete steps taken to ensure that children with disabilities have access to adequate, appropriate and timely healthcare services in their communities?
- What measures has the Ministry of Health taken to ensure doctors and nurses provide parents of children with disabilities with quality information about the health of their child and access to services, including access to health care services, and support in their communities? What concrete steps has the Ministry taken to ensure health care professionals do not advise parents of children with disabilities to place their child in an institution?

We would be grateful to receive your reply by May 2, 2016. If received by this date your response will be reflected in our published material. Your office should not hesitate to respond to our researcher, Emina Ćerimović, via email at cerimoe@hrw.org, fax at +1 212 377 9455 or post at 350 5th Ave, 34th floor, New York, NY, 10018, USA. You are welcome to send your reply in Serbian or English.

We look forward to learning your perspectives on the situation of children with disabilities in Serbia and working with you to ensure their full rights.

Yours sincerely,



Shantha Rau Barriga
Director
Disability Rights Division

Appendix 2: Letter from Ministry 2.b

See Footnote 274

Dear Madam,

We are very grateful to you for the efforts you have invested in drafting the Report on Treatment of Persons with Disabilities at Residential Accommodation Institutions. However, we must stress out that there are a number of inconsistencies, that is to say, illogicalities, so we are hereby pointing out as follows in due sequence:

The Report brings out concern due to the application of psychotropic medicines given to persons with developmental disorders, listing a number of medicines, each of which has its own indicative field of application, and they are prescribed exclusively by psychiatrists based on specific indications. In spite of this, there is a separate opinion corroborating the statement of concern supplied by two unnamed US psychiatrists, while not citing a single opinion by any US professional or expert psychiatric associations. Furthermore, the Report states that psychotropic medicines are given with the aim of controlling the behavior of these children, while ignoring the important fact that prevention of aggression and auto-aggression is performed specifically for the sake of safety and the best interests of the child in the first place.

The Law on Medicines and Medical Materials does not specifically prescribe psychiatric use as information constituting the contents of the license for the medicine, or of the prescribed license form for the medicine. However, the pharmacodynamical and pharmacokinetical properties of a specific medicine are determined on the basis of the assessment of pre-clinical and clinical documentation, and it is defined whether the medicine is intended for use among the pediatric population group and under which indications; the dosage and method of use of the medicine are defined according to the age of children, as well as are the contraindications, special cautions, side effects, and the pharmacodynamical and pharmacokinetical and other data pertaining to the pediatric population group.

This data is cited in the appropriate chapters of the Summary of the Characteristics of the Medicine, Instruction for Use of Medicine and the Labeling Text, which constitute an integral part of the decision licensing the use of the specific medicine. In addition, we emphasize that during the procedure for assessment of pre-clinical and clinical documentation on the medicine (the procedure for licensing of the medicine) also involves the consideration of the information about whether the medicine has been tested according to the approved pediatric research plan, as well as the registration status of the medicine in the EU, in particular for the medicines that are registered on the basis of the centralized procedure in the European Union.

In these terms, there are no guidelines on the application of medicines containing psychoactive controlled substances among children, given that the method of application for these medicines has been defined first in the documentation supplied during the licensing procedure for the medicine, and then also in the Summary on the Characteristics of the Medicine, Instruction for Use

of Medicine and the Internal and External Labeling Texts. The Agency also classifies these medicines based on their regime of issuance, that is to say, which of them are issued on the basis of a prescription exclusively, or else with a special prescription (Article 53).

We hereby point out that the Law on Medicines and Medical Materials prohibits the marketing, and thereby the application itself, of the medicine for which no license to market has been issued in the Republic of Serbia by the Agency for Medicines and Medical Materials of Serbia, as well as that there is appropriate punitive policy in place.

The list of licensed medicines that are applied among the pediatric population group does not exist, but all licenses issued, including their integral parts, have been available on the website of the Agency, and you can also approach the Agency itself in order obtain this information. (<http://www.alims.gov.rs/ciril/lekovi/pretrazivanje-humanih-lekova/>)

As for the segment pertaining to clinical trials of medicines, Article 63, paragraph 1, of the Law on Medicines and Medical Materials prescribes that clinical trials of medicines shall not be conducted on:

- 1) healthy persons who have not become 18 of age;
- 2) healthy pregnant and weaning women;
- 3) persons placed into social protection institutions;
- 4) persons placed into health care institutions or institutions for enforcement of criminal sanctions based on decisions of court authorities;
- 5) persons who under coercion or in another way may be influenced to provide consent for participation in clinical trials or free assent for participation in clinical trials.

Articles 64 through 66 of this Law prescribe the requirements, that is to say, the safeguards for juveniles as well as for persons of age who are not able to provide written consent for participation in clinical trials for medicines. The clinical trials for medicines on juvenile examinees may be conducted if:

- 1) The parent or guardian has provided a written assent (the written assent must constitute an assumption of the will of the juvenile and may be withdrawn at any time without any harm to the juvenile);
- 2) The juvenile has received information which pertains to the course of the clinical trial, the risks and benefits to the health of the examinee, in a way understandable to him or her from a person experienced in working with juveniles;

3) The written assent has been provided without provision of stimulation to take part in the clinical trial by offering or providing any materials or any other considerations;

4) The Ethics Board has assessed that the clinical trial of the medicine on juvenile examinees provides direct benefit for a specific patient group, as well as that such trial is relevant in order to assess the data obtained from clinical trials on persons able to provide written assents independently;

5) On the basis of the opinion provided by a doctor specialized in pediatrics, with a special reference to the clinical, ethical and psycho-social problems involved in the procedure for the clinical trial of the medicine, the Ethics Board has issued a positive decision to conduct the clinical trial of the medicine.

During the procedure of carrying out the clinical trial for the medicine, juveniles able to form their opinion and assess the information obtained on their participation in the clinical trial of the medicine may withdraw their assent at any time or may abandon the clinical trial of the medicine, by providing notice to the chief researcher or member of the research team.

(1) The clinical testing of the medicine on adult examinees who are not able to provide written assent may also be conducted if:

1) The written assent has been provided by the legal representative of the adult examinee who is not able to provide the written assent (the written assent must constitute an assumption of the will of the examinee and may be withdrawn at any time at no harm to them);

2) An adult examinee who is not able to provide a written assent has received information which pertains to the course of the clinical trial and the risks and benefits to the health of the examinee, in accordance with their ability to understand it and from a person experienced in working with such persons;

3) The written assent has been given without stimulation to take part in the clinical trial by offering or providing any materials or other considerations;

4) It has been assessed that the clinical trial of the medicine on such persons provides direct benefit for the patient group whose illness or condition corresponds to their illness or condition;

5) On the basis of the opinion by the doctor specialized in a specific illness or condition of the examinee, or in the patient population group which the clinical trial of the medicine pertains to, with a special reference to the clinical, ethical and psycho-social issues involved in the procedure for clinical trial of the medicine, the Ethics Board has issued a positive decision to conduct the clinical trial of the medicine.

In terms of the statement that a shortage of health workers of certain profiles has been observed at some social protection institutions, we stress out that the Ministry of Health does not determine the quotas on the type and numbers of medical staff at social protection institutions, but that it only judges whether the requirements have been met for the provision of specific forms of health care, and it issues a Decision in these terms permitting the provision of specific forms of health care. Chapter 4 brings out the statement that there is a lack of access to adequate health care for children with developmental disorders and their families, wherein the sole source of this information are three associates in charge of working with families, and the text that follows features interviews with parents who stated they had based the decision to place their children into residential care on the timely access to health care.

The report states that parents among other things also decide to place children into institutions of residential type due to lack of access to adequate services and support groups. Please note that in cooperation with UNICEF and the ministries in charge of social protection and education affairs, the Ministry of Health has passed the Rulebook on Supplementary Educational, Health Care and Social Support to Children and Pupils (Official Bulletin of the RS, No. 63/10) which, among others, envisages the provision of supplementary support to children with developmental disorders as well. Provision of support at local self-administration units is not within the scope of competence of the Ministry of Health.

As for the question in chapter 5, related to the concrete measures undertaken by the Ministry of Health in order to ensure that doctors and nurses do not advise parents the parents of disabled children to place their children into homes, please be informed that in 2008-2011, in cooperation with UNICEF and the Ministry of Labor, Employment, Veteran and Social Affairs, the Ministry of Health has implemented the project titled “Children’s Place is in the Family”, under which 153 health care workers from 21 maternity hospitals and 28 specialized children’s hospitals have passed the basic course, and 50 of them have passed the advanced course, too, in order to provide information on retaining children in the family for the parents of disabled children. During the aforementioned project, a number of campaigns were conducted aiming at awareness raising both among the public and among the professionals involved in children health care about the necessity to ensure care for children with disabilities within families.

Please note that social protection homes are within the scope of competence of the Ministry of Labor, Social and Veteran Affairs, including the supervision over their work.

Best regards,

Acting Assistant Minister
Sladjana Djukic

Appendix 3: Letter from HRW 3.a

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April 19, 2016

Mr. Nenad Ivanišević
State Secretary
Ministry of Labour, Employment, Veteran and Social Policy
Nemanjina 22-26
11000 Belgrade Serbia

CC:
Ms. Branka Gajić
Assistant Minister
Department for Family Care and Social Protection
Ministry of Labour, Employment, Veteran and Social Policy
Republic of Serbia

Dear Mr. Ivanišević,

Thank you for agreeing to meet with us in October 2015 regarding the situation of children and young people with disabilities in institutions in Serbia. We welcome the constructive dialogue between the Ministry of Labour, Employment, Veteran and Social Policy and Human Rights Watch.

Between October and November 2015, Human Rights Watch researchers carried out 118 interviews with children and young people with disabilities, their families, foster care families, civil society organizations, institution staff, legal experts, UNICEF, the Serbian Ombudsperson, Commissioner for Equality and government officials. The research included visits to five large social welfare homes in Veternik, Subotica, Belgrade, Stamnica, and Sremcica, and three small group homes for children and young people with disabilities in Belgrade, Niš, and Aleksinac.

Based on our interviews with the abovementioned groups as well as analysis of Serbian government policies and laws, we have identified a number of concerns that we would like to share with you. We would welcome any information on the efforts of the Ministry of Labour, Employment, Veteran and Social Policy to ensure that children and young people with disabilities enjoy their rights, so that we can reflect this information and perspectives from your ministry in our research. We have also written to other ministries regarding concerns that relate directly to issues within their competencies.

Human Rights Watch would appreciate your response to the following concerns:



HRW.org

1. Over-representation of children with disabilities in institutions and slow progress on moving children with disabilities out of institutions into their communities

Human Rights Watch is concerned that children with disabilities, despite that the majority of them have a living parent, continue to be overrepresented in institutional settings. According to the Republic Institute for Social Protection, as many as 79.9 percent of children in institutions in 2014 in Serbia were children with disabilities, a rise from 62.5 percent in 2012.

Human Rights Watch also found that children with disabilities under the age of three continue to be placed in institutions despite the existing legal prohibition on placement of children under the age of three in institutions. According to local experts and UNICEF, babies continue to be placed in institutions directly from maternity wards.

Human Rights Watch documented that some children with disabilities were moved out of one institution – the Kulina Institution for Persons with Disabilities – yet even in this case, the majority of children were not moved into family care but rather to another institution or to small group homes.

In the 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.¹ However, based on interviews with local activists and directors of three institutions, Human Rights Watch learned that the alleged decrease in the number of children in institutions is a result of children reaching the age of adulthood – and therefore no longer being counted as children – rather than them leaving the institution. Human Rights Watch found that when children with disabilities turn 18, they are either put under “extended parental rights” and continue to live in orphanages for children, or are placed in state institutions for adults.

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

2. Further Investments in Institutions Instead of in Community Support and Services

Human Rights Watch is concerned that the Serbian government continues to invest in institutions instead of community services and support. Human Rights Watch is especially concerned that in March 2014, the Ministry of Employment, Labour, Veteran and Social Policy opened a newly built institution for children and young people with disabilities in Šabac. In April 2016, the Ministry of Employment, Labour, Veteran and Social Policy also opened a new building in the Stamnica Institution for Children and Adults with Disabilities.

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 500,000 Euros) were allocated from the national budget to social welfare institutions for accommodation of children.

¹ 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, 29 September 2014, Page 59, para 363.

We are also concerned on the implications of the central government financing of foster care and institutions from the national budget, while municipalities have the responsibility to develop and finance support services for families. Human Rights Watch documented that this results in a large number of children who live in poorer municipalities, or municipalities who have not committed to this kind of funding, without access to any services.

3. Lack of community support and services for children and their birth families

Human Rights Watch found a lack of community support and services for children and their birth families to prevent unnecessary family separations. According to directors of three institutions where children with disabilities live and parents of children with disabilities were interviewed by Human Rights Watch, poverty and a lack of government-supported services for children with disabilities and their families are the main reasons for placement of children in institutions.

Human Rights Watch documented that where services do exist, they are limited in scope and outreach. For example, the family outreach service, 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.

4. Foster care

Human Rights Watch welcomes the steps the Serbian government has taken to develop and strengthen foster care arrangements. However, according to local experts and a child protection specialist at UNICEF, children with disabilities are more likely to be put in alternative care arrangements than receive support in the birth families.

Human Rights Watch also interviewed five young persons with disabilities who reported experiencing physical abuse, including one case of sexual abuse, while in foster care.

5. Abuses 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 are subjected to a range of abuses in Serbian institutions. These abuses include segregation, seclusion, neglect, unsanitary conditions, lack of privacy, physical and psychological violence, involuntary medical treatment, lack of play and education, denial of legal capacity upon reaching adulthood, and deprivation of liberty.

- Segregation and seclusion

Human Rights Watch documented that 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 two institutions, children were confined to cribs in the same room and wards as adults. In one of the institutions visited, Human Rights Watch found that up to 30 children were confined to cribs in rooms without natural light or fresh air where they spent their entire day. There, up to 11 children were confined to one room, with one caregiver responsible.

In two institutions visited, Human Rights Watch found that children are put 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 that they adapt to the institution.

- **Neglect**

Human Rights Watch is concerned on the lack of individualized attention from caregivers in all large institutions Human Rights Watch visited. Other than taking care of basic needs such as bathing, diaper changes and feeding, there is little or no individual care or stimulation for them. This is likely due in part to the lack of personnel to care for large numbers of children and adults with disabilities.

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, such as child psychiatrists, psychologists, speech therapists and physical therapists.

- **Unsanitary conditions and lack of privacy**

Human Rights Watch documented that there were no showers in the complex of the Stamnica institution where children and young people with disabilities live. The institution staff and the children told Human Rights Watch that institution staff use water hoses to bathe the children. In this institution, there were also no doors or means of privacy separating the toilets in the bathroom. In two other large institutions visited, there were no doors or means of separating showers in the bathing facilities.

In Veternik institution, 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.

- **Physical and Psychological Violence**

While Human Rights Watch documented that many institution staff are well-intentioned and often deeply care for the children, some children and young people with disabilities whom Human Rights Watch interviewed reported experiencing or witnessing various forms of psychological violence by staff or, in the majority of cases, physical violence and insults by peers. Seven children and young people reported experiencing or witnessing beatings by staff, most of which occurred two to three years prior to Human Rights Watch's visits to the institution.

Two young people with disabilities told Human Rights Watch that they recently experienced or witnessed beatings by staff. Other children reported beatings by other people who live in the institutions, usually older residents.

Children and young people with disabilities also described the use of physical restraints by institution staff, often for a prolonged time, but most instances of being restrained or witnessing the use of restraints reported to Human Rights Watch took place a year or more prior to Human Rights Watch's visits to the institutions.

Four children or young people with disabilities who told Human Rights Watch that they

experienced abuse by institution staff or other residents said that they did report the abuse to the institution staff, but that no action was taken.

- **Involuntary and inadequate medical treatment**

Human Rights Watch is concerned about numerous documented cases of inadequate or inappropriate medical treatment in all institutions visited, including involuntary treatment, given to children and adults with disabilities.

Human Rights Watch documented that medication, including psychotropic medications, are used on children with disabilities in Serbian institutions, often as a means of dealing with behavioral issues.

Medical staff at three institutions also told Human Rights Watch about invasive medical interventions they conducted on a number of young women with disabilities without their free and informed consent because they said the guardians of these women had consented to the procedures. 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, anesthesia was used in every case so that the women would not resist the interventions. It is unclear whether any efforts were made to engage the women in discussions about these medical interventions.

- **Lack of play or education**

Human Rights Watch is concerned about the lack of access to education for children with disabilities who live in social welfare institutions. For example, out of 167 children who live in Kolevka Institution, only 23 go to school. None of the 22 children who live in Stamnica Home for Children and Adults with Disabilities attend school.

The few children who live in institutions and receive education attend specialized schools or classrooms only for children with disabilities. Some are also educated within the institution. We are concerned about the quality of this education, segregation from their peers, and added isolation from community life.

We also documented that children who might be formally included in the education system, do not attend school on a regular basis. For example, Human Rights Watch researchers visited all institutions during school hours and found a large number of school-aged children in the institution. The institution staff often claimed that the children's health was too fragile for them to be in school.

We found that many children are excluded from school because they did not start early enough. For example, at Kolevka Institution, a staff member explained that many children between the age of 13 and 15 do not go to school because they are "now beyond the age to enter school."

Human Rights Watch learned that for young people with disabilities, secondary education is not widely available, and where it is available, is limited to vocational training.

- **Denial of legal capacity and limited freedom of movement**

Human Rights Watch is concerned about the large number of persons with disabilities (19,000 according to the Republic Institute for Social Protection) deprived of legal capacity and placed under guardianship. At the same time, children and young persons 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.

Seven young people with disabilities living in institutions interviewed by Human Rights Watch complained about the limited freedom to go outside of the complex of institutions when they wanted.

Human Rights Watch is also concerned on the lack of engagement by legal guardians in the lives of children with disabilities who live in institutions. According to local activists, institution staff, and children and young people with disabilities interviewed, guardians almost never visit or interact with children who live in institutions, particularly when the guardian is a staff member from the Center for Social Welfare.

We would greatly appreciate information about the efforts of the Ministry of Employment, Labour, Veteran and Social Policy with regards to these concerns and what steps, if any, it intends to take to address them. Particularly, we kindly request your responses to the following questions:

- How many children (under 18 years of age) and young people (18 – 26 years of age) with disabilities have been moved out from institutions into the community since 2009?
- How many children with disabilities were moved to institutions for adults upon reaching adulthood in 2015?
- Could you provide information on what are the “justified reasons” a child under age of three can be placed in an institution for longer than two months according to the 2011 Law on Social Protection?
- What steps has the government of Serbia taken to adopt a national comprehensive plan on deinstitutionalization of children and adults with disabilities? What are the reasons why the government of Serbia decided not to adopt the Roadmap to Deinstitutionalization in Serbia proposed by the Protector of Citizens – the Serbian Ombudsman?
- What measures have been adopted at the national level to ensure municipalities have the resources to provide inclusive community services, including support services to children with disabilities and their families, and how have persons with disabilities been involved in these measures?
- What steps has Serbia taken to redirect funding from institutions to community support and services for children with disabilities and their families?
- What was the cost of the newly built institution for children with disabilities in Sabac and from what budget was it built? What was the cost of the newly built building in the Stamnica Institution and from what budget was it built?

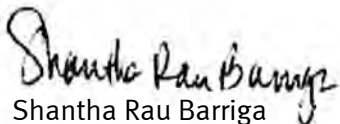
- For what purpose were the 55 million Serbian dinars allocated from the national budget to social welfare institutions for accommodation of children? How much did the Serbian government allocate from the national budget to develop community services and support for children with disabilities and their families?
- In how many cases has family support been provided to a birth family prior to separating a child from its family?
- What steps has the Ministry of Employment, Labour, Veteran and Social Policy taken to support the family outreach service?
- What measures have been adopted to eliminate isolation of children on the basis of their disability and ensure that all children with disabilities living in state institutions are free from discrimination?
- What mechanisms are in place to ensure children and young people with disabilities are free from violence and abuse by institution staff and by peers? What mechanisms are in place to ensure children with disabilities are free from violence and abuse while in foster care?
- Do children with disabilities living in institutions have access to complaint mechanisms to report their treatment? What are the mechanisms for children to file such complaints?
- What concrete measures have been adopted to ensure that health care services, including reproductive health care services, are based on the free and informed consent of the children and adults with disabilities who live in institutions?
- How many women with disabilities living in Serbian institutions have undergone the procedures of insertion of intrauterine devices, administration of pap smear test, and termination of pregnancy with the consent of the guardian, since 2009?
- How many adults persons with disabilities living in institutions of social welfare are deprived of legal capacity?
- How many school-aged children (6-15 years of age), teenaged children (15-17 years of age) and young people (18-26 years of age) with development and intellectual disabilities live in institutions? What percentage of them are out of school? Out of this number, how many children and young people attend special schools or classrooms for only children with disabilities? How many children and young people are educated within the institutions and how does this education meet the same quality of education of other children?
- What practical measures has the Ministry taken to ensure that all children and young people with disabilities have access to mainstream schools?
- What steps has the government taken to ensure officials responsible for education and state institutions for children with disabilities are accountable for progress made toward guaranteeing all children with disabilities access to inclusive education?
- Can you provide us with any information regarding efforts your Ministry has taken to collaborate with the Ministry of Health and the Ministry of Education to ensure the protection of the rights of children with disabilities in Serbia?

- Can you provide us with any information regarding efforts your Ministry has taken to collaborate with the Ministry of Health and the Ministry of Education to ensure access to equitable and inclusive education for children with disabilities in Serbia?

We would be grateful to receive your reply by May 2, 2016. If received by this date your response will be reflected in our published material. Your office should not hesitate to respond to our researcher, Emina Ćerimović, via email at cerimoe@hrw.org, fax at +1 212 377 9455 or post at 350 5th Ave, 34th floor, New York, NY, 10018, USA. You are welcome to send your reply in Serbian or English.

We look forward to learning your perspectives on the situation of children with disabilities in Serbia and working with you to ensure their full rights.

Yours sincerely,

A handwritten signature in black ink, reading "Shantha Rau Barriga". The signature is written in a cursive, flowing style.

Shantha Rau Barriga
Director
Disability Rights Division