

Protecting children from violence and promoting social inclusion of children with disabilities in Western Balkans and Turkey



Situation Analysis: Position of children with disabilities in the Republic of Serbia



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About the situation analysis

Children with disabilities in Serbia, along with their families, require comprehensive and flexible support in order to enable their equal participation in society with other children. Although in recent years significant improvements have been made to the legal framework, children with disabilities still face substantial difficulties with the availability and quality of social, healthcare and educational services, and their families still encounter problems of poverty and insufficient financial support for additional costs related to the disability.

As no comprehensive research has been conducted on this topic so far, this Situation Analysis is an attempt to gather the existing data about the position of children with disabilities in one place with the aim of highlighting the main directions requiring work to improve the position and welfare of these children.

The National Organization of Persons with Disabilities of Serbia (NOOIS) conducted this research within the “Production of situation analysis on the position of children with disabilities in Serbia” project, itself an integral part of the IPA II Project “Protecting children from violence and promoting social inclusion of children with disabilities in Western Balkans and Turkey”. In Serbia, the project was implemented in co-operation with the Ministry of Labour, Employment, Veteran and Social Affairs; the Ministry of Health; and the Ministry of Education, Science and Technological Development, and in partnership with UNICEF and the European Disability Forum, with financial support from the European Union.

The Situation Analysis covers the period 2006 to 2017 and is based on analysis of both secondary and primary data. At the very beginning of the Situation Analysis there were also consultations with state and civil society representatives about topics and the schedule for development of the Situation Analysis.

The Situation Analysis looks at the position of children in the following areas: discrimination, social safety, education, social protection and right to life in a family environment, health protection and protection from abuse and exploitation. It also aspired to include and analyze the following areas: participation and being informed, protection in emergencies, and access to justice, but it did not identify sufficient data to form conclusions. Therefore, NOOIS will continue working on these topics in the upcoming period in order to be able to advocate comprehensively for the improving of policies in relation to children with disabilities, and for their implementation.

After the schedule and structure of the Situation Analysis itself were adopted, the following activities were performed:

- Analysis of secondary data and sources;
- Analysis of international and national legal frameworks;
- Interviews with decision makers;
- Qualitative research with parents through focus groups;
- Quantitative research with parents; and
- Workshops with children.

Implementing the quantitative research “How parents see the position of their children with disabilities: analysis of the application of the Convention on the Rights of the Child“ with the parents was not planned in the initial draft but due to the relatively poor availability of data about the position of children with disabilities and their families, this activity was subsequently added (1). This quantitative research was conducted by means of an anonymous electronic survey with the sample of about 300 interviewees (parents) living in different parts of Serbia.

Each segment of this Situation Analysis begins with a brief summary of the most important findings, which is followed by detailed findings for the relevant area. At the end of the report, basic recommendations are given for various actors at national and local levels, based on the data collected.

The results of the research, which included contributions from a large number of experts from state institutions and civil society organizations as well as a large number of parents and children with disabilities, will serve as a tool to be used by NOOIS and all those involved in improving the position of children with disabilities in the future to strengthen policies in the areas of countering discrimination, social protection, poverty reduction, providing education and healthcare, and protecting children from violence.

ACKNOWLEDGEMENTS

The National Organization of Persons with Disabilities of Serbia (NOOIS), which conducted this Situation Analysis on the position of children with disabilities, would like to thank all the associates and experts from different fields who were involved in various stages of the research, and without whose contribution this study could not have been realized.

We would like to express our special gratitude to Marko Milanović, the main project researcher, as well as many associates who participated actively in collecting and analyzing the research material and making valuable comments and suggestions: Damjan Tatić PhD, Biljana Janjić, Gordana Cvetković, Biljana Kojović, Milica Pejović Milovančević PhD, Žarko Šunderić, Kosana Beker, Ivana Krstić Davinić, Marija Jovanović and Nataša Nikolić. We also thank other associates for their expert and technical support: Ivana Antonijević, Marijana Kraker, Milan Stošić, Svetlana Vlahović, Vesna Petrović, Ljubinka Borizovski, Predrag Bakić and Tatjana Bosnić.

The Situation Analysis is based on information received from a large number of participants in focus groups in Belgrade, Kragujevac, Niš and Vojvodina, from representatives of non-government organizations, many experts in the fields of (non)discrimination, social safety and protection from poverty, social and healthcare protection, education, as well as prevention of and protection from violence.

In addition, it is important to mention the significant contribution of representatives of the Ministry of Health, and the Ministry of Education, Science and Technological Development of the Republic of Serbia, as well as the representatives of numerous institutions such as: The Republican Institute for Social Protection, the Batut Institute of Public Health of Serbia and the Institute for the Improvement of Education and Upbringing, who highlighted issues of providing additional support to children with disabilities from the viewpoints of their respective professional roles.

The research also obtained the opinions of more than 400 parents of children with disabilities who participated in the survey and interviews, as well as the opinions of children who were also involved in workshops adjusted to their age. At this time, NOOIS would like to express its gratitude to all of them for their participation, honesty and desire to improve together the position of children with disabilities in our country.

We offer our special thanks to UNICEF for entrusting us with conducting this analysis. From the very beginning, UNICEF provided full support and throughout the project believed in our capacities for working on this complex task.

We would also like to emphasize the significant contribution made by the European Disability Forum (EDF) within the broader consultation process. With their comments, recommendations and suggestions ED contributed to the final edition of the Situation Analysis.

The draft Situation Analysis and proposed conclusions and recommendations were also presented at four regional meetings – in Niš, Belgrade, Novi Sad and Kragujevac – where the participants' suggestions contributed to additional improvements to the text.

Thank you very much to all of you for your cooperation and contribution!

Ivanka Jovanović,
Project Coordinator and Executive Director of NOOIS

Development of the international and national legal framework

States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right (2).

Convention on the Rights of Persons with Disabilities

Persons with disabilities were not visible for a long period of time: this substantially precluded systematic insight into their conditions and forestalled the finding of adequate solutions for them to improve these conditions and exercise their rights. Since the second half of the twentieth century, initiatives to improve the status of persons with disabilities at international level have been significantly stronger: this led to necessary system reforms being made to respond to the needs and rights of this group of children and adults. The movement of persons with disabilities at the international level has played an important role in this process by, among other things, establishing new standards for public policy planning under the slogan “Nothing about us without us”. This also coincided with a change in the approach to persons with disabilities from the prevailing medical model to the social model. The adoption of the Convention on the Rights of Persons with Disabilities (2) contributed to a different view of the status of persons with disabilities and established firmer strongholds and standards for the observation of their rights. The principles of the Convention include recognition of the evolving capacities of children with disabilities, as well as respect for their right to preserve their identities.

General Comments of the Committee on the Rights of Persons with Disabilities are also of special importance with regard to the status of children with disabilities.¹

The United Nations was particularly active in this field and emphasized the importance of the rights of persons with disabilities even before the adoption of the Convention on the Rights of Persons with Disabilities.² The activities of other international treaty bodies in promoting and protecting the rights of children with disabilities are equally significant. Although the Convention on the Rights of the Child was adopted as early as 1989, children with disabilities, and particularly girls, still faced huge barriers in their enjoyment of rights as a result of social, cultural and physical barriers, as well as prejudice. Therefore in 2006 the Committee on the Rights of the Child (the CRC Committee) issued General Comment 9 on the rights of children with disabilities (3), while in 1991 the Committee on the Elimination of Discrimination Against Women published its General Recommendation 18 about women with disabilities (4). Apart from setting out the framework for the development of policies and practices to improve the position of children with disabilities, CRC Committee General Comment 9 additionally establishes standards in the area of discrimination, on the best interests of children with disabilities, their right to life and progress, their right to opinion, civil rights and freedoms, the right to family environment and alternative care, health protection, education and leisure time, as well as special protection measures. In order to improve the position of persons with disabilities, the Committee on the Rights of Persons with Disabilities introduced a series of general comments to the Convention on the Rights of Persons with Disabilities, the most important of which are General Comment 2 *Accessibility* (5), General Comment 3 *Women and girls with disabilities* (6) and General Comment 4 *The right to inclusive education* (7). In 2008 the Special Rapporteur on Torture submitted a report to the UN General Assembly which for the first time gives clear explanations and recommendations for the protection of persons with disabilities from torture in institutional settings, pointing to the “status of persons with disabilities who are frequently victims of neglect,

¹ In this publication we will use the term “children with disabilities” as a consensus reached with civil society organizations that represent persons with disabilities. “Developmental disorders” will primarily refer to mental disorders and intellectual difficulties, whereas disabilities will mean restrictions to bodily, physical and sensory functioning.

² For example, in 1982 the UN General Assembly adopted the World Programme of Action for persons with disabilities promoting full participation and equality of persons with disabilities in the social life of all countries, regardless of the development status of individual countries. The UN declared the period 1983–1993 to be the Decade of Persons with Disabilities and in 1993 the UN General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

serious forms of restraint and seclusion, as well as of physical, mental and sexual violence”.

This was subsequently supplemented by the attitude that any isolation of children and persons with disabilities, regardless of its length, as well as any physical confinement, was a cruel, inhuman or degrading act (8).

In order to strengthen attempts to recognise, promote, implement and monitor the rights of persons with disabilities in line with an approach oriented to human rights, the position of Special Rapporteur on the rights of persons with disabilities was established in 2014.³

Alignment with other human rights treaties and particularly emphasising the rights of persons with disabilities has also been of great importance. The Council of Europe recognized the significance of this topic and adopted the *Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006–2015*. Based on this plan, in 2006 the Committee of Ministers adopted a recommendation for Council of Europe member states to integrate the principles in their laws and public policies and to take actions (9).

The European Union confirmed its commitment to improve the position of children with disabilities by adopting the Council of Europe Strategy on the *Rights of Persons with Disabilities 2017–2023 “Human Rights: A Reality for All”* (10).

During 2015 the Sustainable Development Goals were agreed at international level in order to respond to three dimensions of sustainable development (environmental, economic and social dimensions) over the period 2015–2030. Improvement of the status of persons with disabilities was emphasized in the areas of quality education, decent work and economic growth, reduced inequalities, making communities safe and sustainable, as well as collecting data and monitoring the Sustainable Development Goals.⁴

An international environment supporting the promotion and exercise of the rights of children and adults with disabilities is an important driver of improved legislation and public policies at national level.

³ Catalina Devandas Aguilar was the first Special Rapporteur on the rights of persons with disabilities. She took up the post on 1 December 2014 after the Human Rights Council adopted Resolution 26/20.

⁴ For more details about the Sustainable Development Goals and the status of persons with disabilities see:

<https://www.un.org/development/desa/disabilities/about-us/sustainable-development-goals-sdgs-and-disability.html>

Alignment with the documents and recommendations of various regional and international organizations and entities leads to clearly formulated recommendations at national level. The Republic of Serbia has ratified almost all international human rights treaties at the levels of the Council of Europe and the United Nations, including the Convention on the Rights of the Child (1990), the Convention on the Rights of Persons with Disabilities (2009) and the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence (2013). In this way it has assumed the obligation to align national legislation with the regulations and recommendations in these documents and made the human rights conventions a part of national legislation.

One of the obligations is regular reporting on how the conventions are applied to international treaty bodies, which then give recommendations for further alignment of laws and improvement of practice in different areas. This has, among other things, led to the establishment of new mechanisms at national level to monitor and advise about the rights of the child.

Given that the Republic of Serbia is in the process of social, political and economic reforms and revitalization and that it is committed to regional integration and cooperation, in 2012 it became a candidate to join the European Union (EU), and accession negotiations began in 2014. The alignment of national legislation and public policies with the EU contributes, among other things, to reforms in various sectors and to improvements in fundamental human rights. The rights of the child with disabilities have been recognized both in the pre-accession negotiation chapters and in the accompanying action plans.

Although Serbia has been working on it for a long time, there is no comprehensive law on children that would more clearly define their position and access to rights.

In addition, a new national action plan is needed for children, as well as a deinstitutionalization strategy.

Thus, in recent years Serbia has substantially reformed its laws and public policies in areas pertinent to the rights of children with disabilities, including making changes in the areas of education, social protection, healthcare, justice and non-discrimination.

National laws are founded on the principles of children rights, non-discrimination and social inclusion, which means they largely meet international standards. At the legislative level the principle of universal design and accessibility was implemented, and support services necessary for independent life in the family environment, including comprehensive support for education, were defined. Moreover, various mechanisms were stipulated to increase the employment opportunities of persons with disabilities. In general, the laws generally recognize independence, life in the community and dignity of children with disabilities as the most important principles. Significant efforts were made under the overall reforms so as to ensure mechanisms for implementing new affirmative measures for members of vulnerable social groups.

However, it should be emphasized that unfavourable macroeconomic indicators and small budgetary allocations for the rights of children with disabilities make this process to a large extent dependent on donor funds from the international community: this may adversely affect the sustainability of reform processes.

The laws and public policies crucial for children with disabilities are primarily within the competence of line ministries, their decentralized entities and local self-governments. In 2002 the Government of the Republic of Serbia established the National Council for Child Rights as a multi-sector body made up of representatives of the relevant ministries, civil society organizations and independent experts and mandated it with the task of taking initiatives, giving opinions and proposing measures for the realization of the rights of children in the Republic of Serbia. However, the Council has had very few sessions since 2014. In 2017 the Committee on the Rights of the Child expressed concern over the body only having an advisory role, and not meeting sufficiently often, while its functioning was observed as “inconsistent and lacking focus” (11).

Furthermore, in 2012 the Serbian National Assembly established the Committee for Child Rights, which is mandated to monitor and ensure inclusion and observance of children’s rights in all legislative texts. The protection of the rights of the child in Serbia has certainly been improved by the establishment of independent institutions such as the Ombudsman (who has a deputy for children rights and another for the rights of persons with disabilities), the Regional Ombudsman, the Commissioner for the Protection of Equality and the Commissioner for Information of Public Importance and Personal Data Protection.

Basic information about children with disabilities in Serbia

Serbia is a country of 7,186,862 inhabitants, of whom 17.6 per cent are children. The number of children with disabilities is not known. Although the 2011 National Census also collected data about the number of persons with disabilities, the methodology applied was inadequate on persons with disabilities, including children, and so it found that children with disabilities make up only 0.7 per cent of the total child population, whereas the generally accepted estimate is that children with disabilities constitute 5 per cent of the child population. It is difficult to establish the exact number of children with disabilities because of the lack of agreement between the definitions of disabilities in different laws as well as the underdevelopment of instruments to estimate the population size that would be in compliance with the Convention on the Rights of Persons with Disabilities. In this context, it is encouraging to follow the work to develop the Register of Children with Disabilities by the Ministry of Health and the Batut Institute of Public Health of Serbia. After its anticipated completion in 2018, the Register is expected to contribute significantly to clearly determining the number of children with disabilities in line with good international practice in this area and to introducing functional assessment of disabilities based on the International Classification of Functioning, Disability and Health developed by the World Health Organization.

The Republic of Serbia has been an independent state since 2006. In the period following 1992, after the break-up of the Socialist Federal Republic of Yugoslavia (SFRJ), it constituted the Federal Republic of Yugoslavia together with Montenegro and then between 2003 and 2006 the State Union of Serbia and Montenegro.

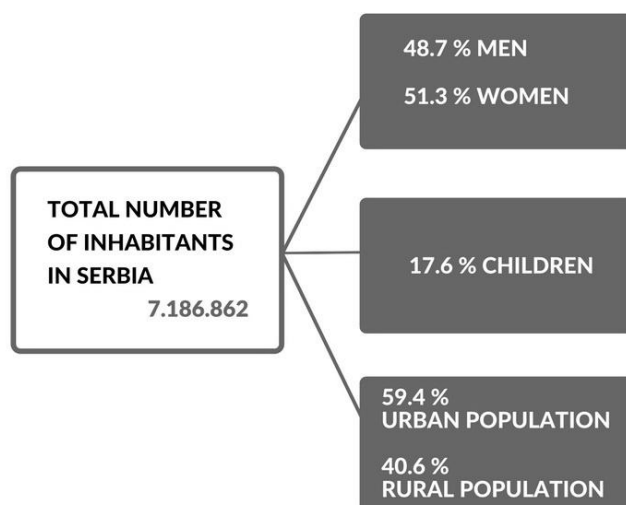
Serbia is situated in the Balkan Peninsula and according to the 2011 National Census from 2011, the Republic of Serbia had a total of 7,186,862 residents,⁵ of whom 1,263,128 were children (12), while and the average age was 42 years.

⁵ The estimated number of inhabitants on 1 January 2017 was 7,040,272, <http://webrzs.stat.gov.rs/WebSite/Public/PageView.aspx?pKey=162>

The Republic of Serbia is a medium-development country with a gross domestic product (GDP) of US\$ 5,333 per capita. The rate of real growth of GDP rose from 0.8 per cent in 2015 to 2.8 per cent in 2016 (13).

According to the International Labour Organization, Serbia allocates about 20.9 per cent of GDP to social protection, including healthcare services. Equivalent allocations are higher in neighbouring Croatia (26.5 per cent) and Montenegro (23.0 per cent) (14).

Figure 1: Demographics of Serbia



The number of inhabitants in Serbia is decreasing. The rate of natural increase is negative (-5.1 per cent between 2006 and 2016) and the most significant natural decrease over this period was recorded in Southern and Eastern Serbia region (-7.8 per cent).⁶ In 2016 Serbia had 39,500 less children than in 2011, while the total population had fallen by 128,540.

There is little difference between the number of children (under 18 years old) and inhabitants older than 65, which ranks the population of Serbia among the oldest in

⁶ Vital events in 2016, Statistical Office of the Republic of Serbia, <http://webrzs.stat.gov.rs/WebSite/public/PublicationView.aspx?pKey=41&pLevel=1&pubType=2&pubKey=4230>

Europe. A total of 59.4 per cent people live in urban environments, with 40.6 per cent living in rural (other) environments (12).

Although the average unemployment rate in Serbia is decreasing year on year, it is still rather high, standing at 17.7 per cent in 2016, while the unemployment rate of young people (aged 15–24) was 43.2 per cent.

Children in Serbia are one of the groups most vulnerable to poverty. The poverty risk rate among children is 29.9 per cent compared to 25.4 per cent for the population as a whole (15). Children are subject to multiple risk factors, with the largest proportion being subject to both poverty and material deprivation. The risk of serious material deprivation is most prevalent in single-parent households (45.3 per cent) and families with three or more children (36.1 per cent). With regard to monetary poverty, 30 per cent children are still at poverty risk even after social transfers. Monitoring of absolute poverty revealed that 8.9 per cent of Serbia's population lived in absolute poverty in 2014: and that the percentage was twice as high in rural than in urban environments. The most vulnerable are children aged 13 or under (12.2 per cent) and children between 14 and 18 (11.5 per cent), with regional differences sharply pronounced – from 4.7 per cent in Belgrade to 17.6 per cent in Eastern and Southern Serbia (16). The Gini coefficient (the indicator for measuring inequality) is rather high in Serbia, and in 2016 it was 16.13 (17).

In Serbia there is no standard definition of disability used in laws and public policies. The most comprehensive definition in line with the social model and the definition in the Convention on the Rights of Persons with Disabilities appears in the Law on Prevention of Discrimination against Persons with Disabilities. In this Law “persons with disabilities” are defined as persons with congenital or acquired physical, sensory, intellectual or emotional (psycho-social) impairment who are, due to social or other barriers, unable or have limited opportunities to engage in social activities at the same level as others, regardless of whether they are capable of carrying out such activities with the use of technical aids or support services (18).

This definition is in compliance with the social model of perceiving disability, which takes as its starting point the idea that disability is a social construct, i.e. that disability is a product of a society which sets various architectural, physical, informational and attitudinal barriers to persons with disabilities, and thus disables their adequate and full participation in the society on an equal basis with others. The absence of a uniform terminology, definition and classification of disabilities and developmental disorders certainly hinders the collecting of precise information about children with disabilities. Different sectors and government departments use different definitions and classifications.

For example, the education system mostly relies on three categories set out by the Organisation for Economic Cooperation and Development (OECD) for schoolchildren with special educational needs: children with disabilities are in Group A; Group B consists of children with learning and behavioural difficulties, while Group C is children from socially non-stimulating environments (less-favoured environments) (19). On the other hand, in line with general requirements, Serbia's healthcare sector uses the International Classification of Diseases 10 (ICD-10).

The use of the International Classification of Functioning, Disability and Health (ICF) is increasingly promoted and advocated. The ICF was developed by the World Health Organization and it perceives disabilities primarily through assessment of damage to body structures, functions and opportunities of participation in the community, and not only through diagnosis: this is in line with the Convention on the Rights of Persons with Disabilities.

The use of different classifications is justified and reasonable given professional requirements and the aim of providing support to children with disabilities. However, it inevitably leads to different data keeping methods. Moreover, the data collected are not disaggregated by gender, age, type of disability or other characteristics, and this makes monitoring the status of children with disabilities in Serbia even more challenging. In this context, the Committee on the Rights of Persons with Disabilities has also recommended that Serbia should "update and collect data and statistics about persons with disabilities sorting them by age, gender, type of disability, ethnicity and place of residence, including type of residential or institutional accommodation as well as reported cases of discrimination or violence against these persons, while using the approach based on human rights" (20). Establishing a unique and centralized database about children would be hugely significant: this has also been recognized by the Committee for the Rights of the Child, which recommended that apart the already-listed characteristics, Serbia should also collect data sorted by socio-economic conditions "in order to facilitate the analysis of the situation of all children, particularly those in situations of vulnerability" (11). An extremely important activity in this regard is the development of the Register of Children with Disabilities. After its anticipated completion in 2018 the Register should contribute significantly to a clear determination of the number of children with disabilities in line with the ICF criteria.

The lack of disaggregated data, among other things, makes it more difficult to understand the situation of children with disabilities in the most vulnerable situations, such as children in residential institutions, especially children with intellectual, mental and multiple disabilities, children living in poverty, unaccompanied minors and children working in the streets or on the move.

Although there are not always quantitative and qualitative data about the number, characteristics or status of these groups of children, available data show that these children are exposed to multiple discrimination based on personal features, are exposed to violence and neglect to a greater degree, have particularly difficulty accessing their rights and are exposed to the risk of social isolation.

However, it should be noted that significant attempts have been made in Serbia in this field in recent years and that now there is more information available about children with disabilities. For example, the 2011 National Census for the first time introduced questions regarding disabilities, following the recommendations of the Washington Group on Disability Statistics, and various sectoral reports and databases also provide useful information. According to the census data, nearly 8 per cent of the population reported having a disability (21).

The Census results referring to the number of children with disabilities and their characteristics should be viewed with caution because the methodology applied was not adequate for assessing functionality with regard to disabilities in children.

According to the Census, children with disabilities made up only 0.7 per cent of children up to 15 in Serbia and only 0.1 per cent of the total recorded population. This percentage seems rather low, as it is assumed that children with disabilities account for about 5 per cent of the child population. Five per cent will be used in this publication as the starting point for assessing the inclusion of children in services. Estimates of the number of children with disabilities at the international level show substantial deviations resulting from the definition and method of measuring disabilities. The World Health Organization (WHO) estimates that the number of children between 0 and 14 years old with moderate or serious disabilities is approximately 93 million (5.1 per cent of all children in this age category), while about 13 million children (0.7 per cent) have pronounced developmental disabilities. The child's functioning must not be perceived separately but within the context of the family and the environment they live in. The WHO recommends the use of the International Classification of Functioning, Disability and Health (ICF) because it ensures a common platform for collecting and measuring data by different social sectors. ICF is the basis for harmonizing the approach to the disability prevalence evaluation because it enables the collection of data about the number of children with various levels of difficulties in functioning within developmental domains (motor, socio-emotional and cognitive domains, the functioning of senses and so on). The level of functional difficulties, where serious difficulties or complete absence of functions in any of these domains are taken as the threshold for the existence of disabilities, is an understandable category in all sectors and a good basis for planning support measures. Prevalence is the result of complex and dynamic contextual factors, both personal and environmental (22).

Discrimination

In the past ten years significant progress has been made in improving the legal framework and equality of children with disabilities in Serbia. However, children with disabilities still face substantial barriers to their inclusion in society. Children with disabilities and their families frequently encounter negative attitudes, and 45 per cent of parents state that either they or their children have experienced some kind of insults, degrading treatment or harassment due to the children's developmental disabilities. Moreover, 29 per cent of children with disabilities have experienced refusal when trying to use public services because of inaccessible facilities or unadjusted conditions, and 8 per cent experienced this in the past year, 26 per cent stated they had been discriminated against because of special conditions being set that amounted to indirect discrimination, of whom 10 per cent had experienced this in the past year. Children with physical disabilities are most often exposed to this form of discrimination. Discrimination most often relates to the education system, which children have the most contact with. The substantial level of negative attitudes can also be seen in the results of the MICS 4 research, which show that one third of the population (32 per cent) think that children with mental and intellectual disabilities have a negative effect on other children, while the same opinion is shared by a quarter of the population (23 per cent) regarding children with physical and sensory disabilities. However, there is encouraging information that more than 90 per cent of the population think that with adequate support children with disabilities can make great achievements in their lives.

The Convention on the Rights of the Child obliges all the signatory parties to ensure all the rights of the child within their jurisdiction regardless of the "race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status of the child, his/her parents or legal custodian(s)". This includes a prohibition on discrimination against the child's parents, custodians or members of the family (23). Discrimination on the basis of disability is more closely defined in the Convention on the Rights of Persons with Disabilities in Article 2 as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field".

Article 2 also covers all forms of discrimination, including denial “of reasonable accommodation” (2). The state, among other things, is obliged to provide reasonable accommodation, as well as special measures necessary for expediting or achieving de facto equality of persons with disabilities. Since in Serbia the decentralization principle has been implemented to various degrees in different systems, in interpreting the situation in each area it should be remembered that the state is has obligations concerning discrimination against children with disabilities, regardless of the degree of decentralization. It should also be pointed out that the Convention states that girls with disabilities are exposed to multiple discrimination, and that therefore additional measures should be taken to support girls with disabilities.

In Serbia 8 per cent of people believe that persons with intellectual difficulties and mental disorders are the group in society most exposed to discrimination, while 5 per cent believe this about persons with physical and sensory disabilities.

Persons with intellectual difficulties and mental disorders are the fourth most vulnerable group ranked by social distance in Serbia. This is particularly found in the areas of work, education, socializing and marriage (24).

Although at the system level significant changes have been introduced with the intention of improving the position of children with disabilities towards enjoying their rights on an equal basis with others, these comprehensive changes are not easily accepted and realized in a short period of time. For many decades children with disabilities were suffered exclusion and segregation because the system was mainly based on the medical model and segregated services were in place only for children with disabilities, a situation characteristic of Central and Southeaster Europe (25). This approach also prevailed in education⁷ and social protection,⁸ whereas a high level of exclusion and segregation of children with disabilities led to their invisibility, insufficient interaction with children in the broader population and general lack of experience regarding life in the community.

⁷ For example, UNICEF estimates from 2001 show that as many as 85 per cent children with disabilities were completely excluded from the education system.

⁸ Relying on institutionalization as the prevailing form of social support to children and persons with disabilities.

This long-standing practice led to the development of stereotypes and prejudice towards this group of children, which today significantly affects their equality and acceptance in society.

As many as 53.6 per cent of interviewees from the healthcare system in Vojvodina believed that persons with Down Syndrome should live in institutions, while the large majority (87.6 per cent) believed that persons with Down Syndrome could not live independent lives, finish school or be trained for work (26).

The survey of public attitudes to discrimination show that every year persons with disabilities are regarded as one of the groups most discriminated against (24). Thus, 8 per cent of Serbian men and women think that persons with intellectual difficulties and mental disorders are the most exposed to discrimination in our society. When directly asked which group of male and female citizens they regard as the most vulnerable, the interviewees reply that those are Roma (20 per cent) and LGBT individuals (16 per cent), followed by the poor (11 per cent), women (8 per cent) and persons with intellectual difficulties and mental disorders (8 per cent). Only 2 per cent of the interviewees think that children are discriminated against in Serbia, while just 0.1 per cent gave children as their first answer regarding a discriminated group⁹. Belgrade citizens (19 per cent) and citizens of Šumadija and West Serbia (17 per cent) more frequently perceive persons with disabilities to be the group which is discriminated to the largest extent.

In relation to the intensity of social distance, persons with intellectual and mental disabilities are in the fourth place, while the intensity of social distance to persons with physical and sensory disabilities is quite low (24). However, social distance changes drastically in relation to the area of life and the assumed role of a person from a certain group of citizens (Table 1).

⁹ Since it is the analysis of the citizens' perception and not of the frequency of discrimination, this finding may indicate that citizens generally do not recognize or understand discrimination against children itself.

Table 1: Social distance to persons with disabilities in 2016

	Person with physical and sensory disabilities	Person with intellectual difficulties and mental disorders
Would you mind having this person as your neighbour?	2.5%	1.5%
Would you mind having this person as your co-worker?	2.8%	8.7%
Would you mind having this person as your children’s educator?	5%	28.9%
Would you socialize with or visit this person?	1.7%	6.4%
Would you mind your or your child being married to this person?	15.4%	35.6%

It is concerning that as many as 16 per cent of citizens think that discrimination against certain groups is acceptable. This attitude is expressed by 18 per cent of male and female students in Serbia and is more present in small towns. Nevertheless, it is positive that 96 per cent of interviewees think that persons with disabilities should be given unobstructed access to all facilities and buildings where public services are rendered.

For the purposes of producing this Situation Analysis, parents of children with disabilities were interviewed about various topics defined as key topics for improving the everyday life of the child. As many as 45 per cent of the interviewed parents stated that either they or their children had experienced insults, degradation or harassment due to their children's developmental disabilities. Most frequently children are exposed to such treatment by unknown persons/passers-by (28 per cent), then by peers attending the same school (17 per cent). However, they also experienced them from school staff (7 per cent), health workers (8 per cent) and providers of public transport services (8 per cent). Being subject to insults and degradation is loosely connected with disabilities, and children with hearing disabilities are substantially less exposed to discrimination (13 per cent), while children with physical disorders are most exposed to this form of discrimination (59 per cent).

Twenty-three per cent of interviewees think that children with physical and sensory disabilities have a negative effect on the everyday life of other children in the family, while 32 per cent have the same opinion about children with intellectual disabilities.

However, as many as 91 per cent of interviewees think that children with intellectual disabilities are able to achieve many things in life if they have adequate support, while 95 per cent of interviewees have the same opinion about children with physical and sensory disabilities (27).

Negative attitudes often lead to rejection and discrimination. In the case of children, particularly children with disabilities, this has been recognized in various areas of life.

Data from the Commissioner for the Protection of Equality show that children with disabilities are a particularly endangered group in Serbian society and that stereotypes and prejudice about their abilities, needs and rights are deeply rooted and widespread (28).

According to research conducted by the Commissioner for the Protection of Equality's institution, 60 per cent of public officials think that persons with disabilities in Serbia are discriminated against. However, it is concerning that 22 per cent of representatives of executive and legislative authorities did not know that discrimination was prohibited in Serbia, and that 48 per cent of the interviewees expressed their belief that groups who are discriminated against are solely responsible for their own position, an indication of a tendency to relative the responsibility of the state and society (29).

In this respect, the Committee on the Rights of Persons with Disabilities has also expressed concern about the lack of campaigns in Serbia to raise awareness and fight against harmful stereotypes and widespread discrimination. The Committee has recommended that the state should "implement awareness-raising campaigns, with the involvement of persons with disabilities and their representative organizations, and actively promote a positive image of persons with disabilities by focusing on their skills and talents. Those campaigns should target the general population, public officials and the private sector, as well as educational institutions, in accessible formats." (20).

The Committee on the Rights of Persons with Disabilities has expressed concern about non-systematic implementation of anti-discrimination legislation in Serbia.

The concept of reasonable accommodation and recognition of denial of such accommodation are not regarded as a form of discrimination in the anti-discrimination legislation (20).

In recent years national legislation to protect against discrimination has been completed in Serbia. The Law on the Prohibition of Discrimination (30) regulates the general regime of prohibition of discrimination, while there are separately-defined provisions prohibiting discrimination against children and discrimination on the basis of disability in political, economic and cultural aspects, as well as in aspects of public, professional, private and family life. Protection of persons with disabilities is regulated in more detail in the Law on the Prohibition of Discrimination of Persons with Disabilities, while the Law on Gender Equality is also significant for equality. Prohibition of discrimination also explicitly appears in other laws regulating special areas such as education, social protection, healthcare, sport, culture and volunteering. Public policies established to prevent discrimination and reduce inequality include, among others, the *Strategy for prevention and protection against discrimination* (2013) and the accompanying Action Plan for implementing the Strategy (2014–2018), which recognize the unfavourable status of children with disabilities and develop measures for improving their equality.

During 2010 the institution of the Commissioner for the Protection of Equality was established as an independent, autonomous and specialized public body with the tasks of preventing all types, forms and cases of discrimination, protecting the equality of natural and legal entities in all spheres of social relations, monitoring the application of regulations about prohibition of discrimination, and improving implementation and protection of equality.

According to data from this institution,¹⁰ disability-related discrimination has always ranked among the top four grounds by the number of complaints filed. In the course of 2016 there were 82 complaints filed because of disability-related discrimination, which accounted for 12.9 per cent of the total number of complaints filed. Of all filed complaints, natural persons filed 61 (36 by men and 25 by women), while organizations filed 14 complaints. The Commissioner emphasizes that persons with disabilities mostly encounter discrimination in the fields of education and professional training (24 complaints), provision of public services or use of facilities and space, in recruitment procedures or at work, and in interactions with officials.

The number of complaints to the Commissioner for the Protection of Equality is clearly not the only indicator of discrimination, especially if we take into consideration the large number of citizens who are still not familiar with the phenomenon of discrimination or the role of this institution. However, these data provide an insight into the areas of life where families and persons with disabilities face discrimination.

Other reports and analysis show that persons with physical, intellectual and mental disabilities belong to the most vulnerable social groups and are exposed to discrimination in all fields of social life (31). Although it is clear that public campaigns, and generally activities intended to eliminate discrimination, are crucial for alleviating stereotypes and prejudice towards children with disabilities it is equally important to include children with disabilities actively and fully in all aspects of life so that attitudes in society can be changed through social interaction, getting acquainted and living together. According to the research with parents of children with disabilities, we may conclude that discrimination in the form of not being able to enjoy services because of inaccessibility of buildings or inadequate conditions was experienced by 29 per cent children, while in the past year provision of services was denied to 8 per cent of children with disabilities (32). If multiple discrimination regarding provision of services is defined as refusal to provide services in more than one system, it can be concluded that 4 per cent of children were exposed to multiple discrimination in service provision.

¹⁰ These data are provided in the 2016 Regular Annual Report of the Commissioner for the Protection of Equality, Belgrade, March 2017.

Figure 2. Has your child ever been denied provision of any services because the buildings or instruments of work were not adapted to children with disabilities?

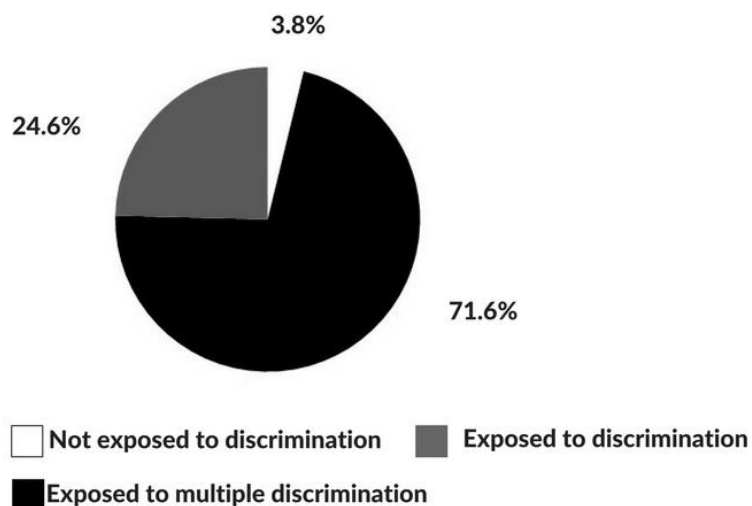
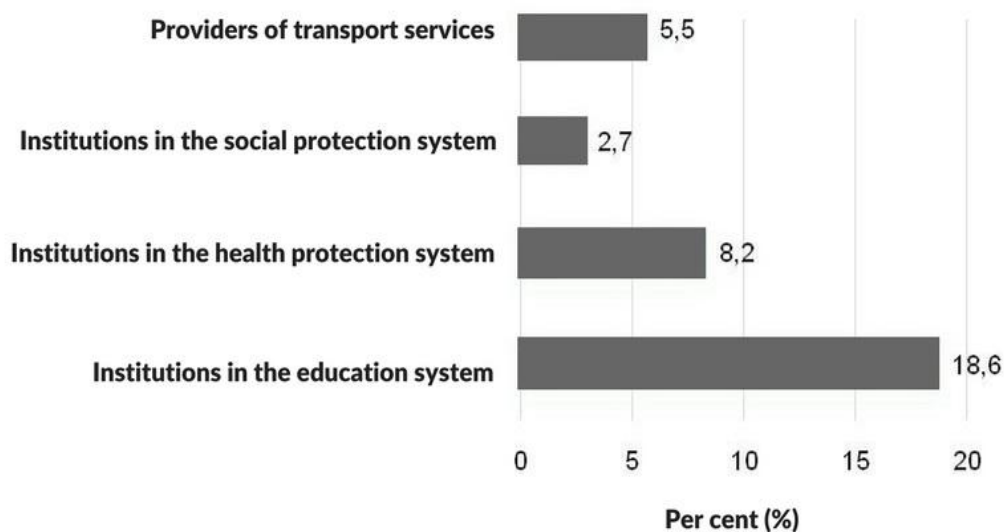
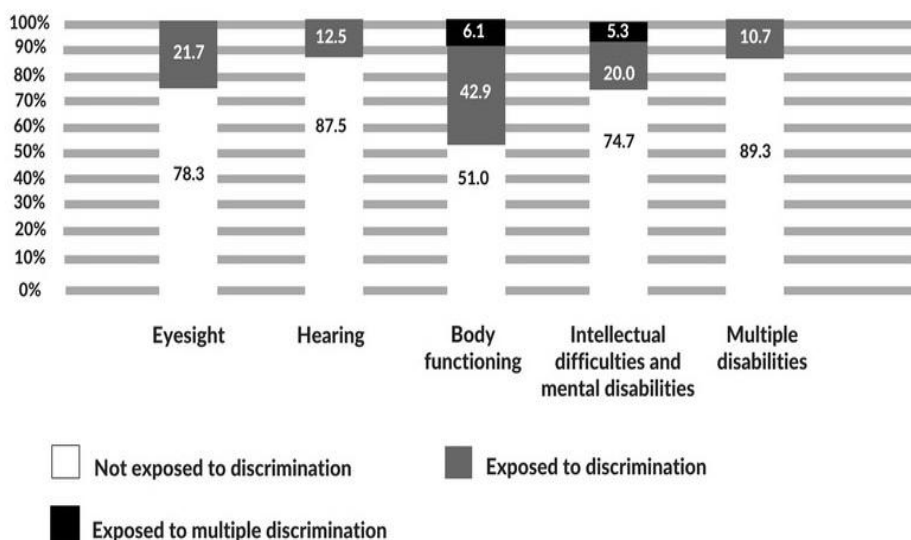


Figure 3. Has your child ever been denied provision of any services because the buildings or instruments of work were not adapted to children with disabilities? [by type of institution/service]



Children most frequently experience discrimination in the education field, then in health. This is expected given that children have the greatest contacts with these two systems. The services were most often denied to children with physical disabilities.

Figure 4. Has your child ever been denied provision of any services because the buildings or instruments of work were not adapted to children with disabilities? [by dominant type of disability]



Children with physical disabilities, intellectual difficulties or mental disorders were exposed to the highest degree of discrimination due to inadequate instruments of work.

Indirect forms of discrimination – setting special criteria that make services difficult or impossible to access for children with disabilities – have been experienced by 26 per cent of children, or 10 per cent in the course of the past year. At least one form of discrimination on the ground of disability has been experienced by 61.2 per cent of children with disabilities or their parents, while multiple discrimination has been experienced by 38 per cent of children with disabilities (32).

Poverty and social security

Although there are no official data about poverty among children with disabilities and their families, children and persons with disabilities in Serbia are exposed to poverty to a larger extent than other population groups. Financial aid and support programmes to cover disability-related costs for persons with disabilities who live in poverty are not sufficiently developed. Although the law regulating residential support recognizes persons with disabilities as users, families of children with disabilities are not entitled to this type of support. Sixty per cent of families of children with disabilities say that their family incomes are insufficient to provide adequate care to their children. The size of additional funds allocated for childcare are roughly estimated in the survey conducted for the Situation Analysis. The results show that these allocations are on average 25,000 dinars, and that families put aside the smallest amounts of money for participation in social protection services, and the largest amounts for medical treatment and purchasing products necessary for everyday childcare. Although parents were reluctant to give up their jobs, in 24 per cent of the families a parent had to stop working because of the increased childcare costs, while parents frequently encountered lack of understanding from their employers of the additional obligations imposed by childcare.

Poverty is often recognized as a structural cause of exclusion and deprivation of various population categories. Because of the negative consequences of living in poverty, the first Sustainable Development Goal is *ending poverty in all its forms* and includes the aim of by 2030 at least halving the share of men, women and children of all ages who live in poverty in all dimensions, in line with national definitions. World Bank studies indicate that persons with disabilities account for about 20 per cent of people living in poverty, and that children with disabilities are exposed to a higher risk of chronic poverty (33, 34).

The Convention on the Rights of the Child stipulates the right of the child to a living standard that suits the child's physical, mental, spiritual, moral and social development, while the state is obliged to, if necessary, undertake measures to help parents and other persons in charge of the child by providing material aid and programmes, particularly regarding food, clothes and accommodation: this also includes the acquisition of adequate furniture and assistive technology for the child to live a dignified and independent life (23).

Moreover, the Convention on the Rights of the Child also stipulates the right of the child to social protection and social insurance. This should, if possible, take into consideration the position of both the child and the persons in charge of his/her livelihood. The Convention on the Rights of Persons with Disabilities additionally stipulates that persons with disabilities, and particularly women and girls with disabilities, should have access to poverty-reduction programmes and that persons with disabilities and their families living in poverty should have access to government aid for covering disability-related costs, as well as access to social housing programmes (2).

Children poverty is a serious problem in Serbia. According to the 2014 Survey on Household Consumption, the rate of absolute poverty among young people aged up to 13 is 12 per cent, compared to 9 per cent in the general population (17). However, extant statistical studies do not systematically cover issues affecting persons with disabilities. Although insufficient, the most complete data about poverty among persons with disabilities can be found in the Living Standards Measurement Survey (LSMS).¹¹ Data from 2007 show that about 8 per cent of persons with disabilities lived below the poverty line, compared to 7 per cent of Serbia's population as a whole (35).

Given the increased household expenditure needed for children with disabilities, such as funds for various aids, special transportation, specific nutrition, and medicines not (fully) covered by health insurance, it may be assumed that the level of poverty of these children is even higher. The quantitative survey conducted with the parents for this study found that 26 per cent of families felt their economic situation to be poor or very poor, while as many as 60.1 per cent stated that their family earnings were insufficient to cover additional costs related to care for children with disabilities (32).

On average, according to the survey, families allocate about 25,000 dinars per month, ranging from 2,000 to 100,000 dinars. They put aside the smallest amount of funds for the participation in social protection services and the largest amount for treatment and purchasing products necessary for everyday child care (32).

¹¹ However, the greatest challenge is the fact that LSMS is not a regular survey by the Statistical Office of the Republic of Serbia. It was conducted in several cycles, but not in the past 10 years (the LSMS was conducted in 2002 and 2003 by a private company, and in 2007 by the Statistical Office). Nevertheless, in the absence of other data, for the purpose of this initiative we quote the data from the latest LSMS in order to get a general idea about poverty among children with disabilities in Serbia. [Living Standards Measurement Survey 2002-2007, Statistical Office of the Republic of Serbia, 2008 (Belgrade: Publikum)].

Since families lack sufficient support for childcare, in 24 per cent of cases a parent had to give up work to take care of his/her child's daily needs. This further limits family income by about 16,500 dinars per family member (32). The most common source of family income is the supplement for care and assistance by another person (73 per cent) and then employment (71 per cent), while monetary social assistance is received by 9 per cent of families of children with disabilities (32).

Regular surveys conducted by the Statistical Office of the Republic of Serbia do not contain official data about poverty among children with disabilities.

The methodological approach to calculating the level of poverty of persons with disabilities, particularly children with disabilities, is a special challenge.

Inclusion of parents of children with disabilities in the labour market is also aggravated by lack of understanding on the part of employers of the additional obligations of such parents regarding childcare, while parents find it difficult to terminate employment because of additional childcare costs.

"It is not all about money, but unfortunately our healthcare system has changed so that you have to go to a private doctor and you need money to solve something. My wife wanted to quit her job but I gave her two arguments against it: no matter which door we knock at, we can't do without money. The second argument was that she needs to get away from our harsh reality if only for five minutes, because it will mean something to her."

Father of a child with disabilities

"For example, after my daughter's operation my boss, the owner of the company, told me I couldn't take a day off when I was supposed to bring her home from hospital. It was the end of the year, in December, and I had already used all my days off. He wouldn't let me go and told me to choose between my child and the job. So I had to find someone else to go to hospital instead of me and take my child and my wife."

Father of a child with disabilities

"I don't let myself ask for sick leave. I don't go on my annual vacation. So when I need a day off because of my child, I take it from the vacation days I saved."

Mother of a child with disabilities

In Serbia there are several forms of material support for families of children with disabilities that are important to both children with disabilities and their families.

Monetary assistance aimed at reducing poverty is allotted after examining someone's financial situation and is financed from national level. It includes monetary social assistance and child benefits. Local self-governments are mandated to provide one-off monetary assistance, assistance in kind, and other types of material support that can also be seen as measures aimed at poverty reduction. The supplement for care and assistance from another person as well as the increased supplement for care and assistance from another person are benefits allotted without examining someone's financial situation because they are derived from the social protection system and are intended for persons with disabilities, including children with disabilities, for ensuring support services (36).

Serbia allocates funds almost half the average expenditure of this type in the European Union for expenditure intended for children and families: 1.2 per cent of GDP, compared to the EU-28 average of 2.3 per cent. According to 2012 data, 0.33 per cent of GDP was allocated for child benefit and only 0.04 per cent for supplements for care from someone else and assistance by another person (37).

Monetary social assistance is defined as for “an individual or a family which through its work, income from property or any other source earns a sum smaller than the amount established in this Law” (36). Analysis of monetary assistance for children and families with children in Serbia indicates that it is given to a small number of users (about 7 per cent of children in Serbia) and that the annual income of families of children with disabilities from the monetary social assistance are low, as the volume of assistance only reaches net minimum earnings for families with four children.

Recognizing that this assistance is not adequate, and particularly to improve the protection of children with disabilities in the poorest families (37), this analysis suggests increasing the amount allotted to children with disabilities in the poorest families. This is because in Serbia, with the exception of increased child benefit, there are no other instruments to protect the material status of this particularly vulnerable group. Such a change could also ensure that the assistance reaches a larger number of children and better targeting.

The child benefit programme is a monetary allocation designed for families with children with low incomes, and is allotted after examining the family's financial situation. Special benefits are stipulated for children with developmental disorders or disabilities and for children of single parents, foster parents and custodians.

The benefits are as follows: a person over the age of 19 and up to the age of 26 may also receive child benefit provided that the individual has disabilities and is participating in a special training programme; the income threshold is increased by 20 per cent for single parents, foster parents, custodians and parents of children with disabilities; the amount of child benefit for children of single parents, foster parents and custodians, as well as for children with disabilities is increased by 30 per cent and in cases with multiple grounds by 69 per cent (37).

Of the 382,900 children who receive child benefit, a large number are granted this right under more favourable conditions and receive increased child benefits: in 2012 there were 80,900 children with higher child benefits, or 21 per cent of the total. This included about 4,000 children with disabilities. Very few children who are vulnerable on two grounds are entitled to the increase of 69 per cent. Those are, almost exclusively, children with disabilities in single-parent families, and account for less than 2 per cent of all children with the right to increased child benefit (37).

Recognizing the special vulnerability of children with disabilities, the analysis suggests introducing universal child benefit for these children and increasing its size by 50 per cent.

An important means of supporting families with young children is the so-called “parent benefit” which is universal for all parents with newborn children and is a measure of population policy.

The size of parent benefit is higher than in most EU member states where this assistance to parents is paid as a one-off allocation. After legislative amendments in 2005, this benefit in Serbia is paid one-off only for the first child, while for other children the allowance is paid in 24 monthly instalments. Approximately 60,000 families receive parent benefit and another 36,700 individuals receive compensation during leave after the childbirth.¹² From 2012 onwards a small number of parents of children with disabilities started receiving special compensation as a form of social pension¹³ (37).

¹² Mothers may use both forms of compensation and that is why these two forms partially overlap.

¹³ According to the Law on Social Protection, one of the parents who is not employed and who has for at least 15 years taken direct care of his/her child with the right to increased compensation for assistance and care of another person, is entitled to special monetary compensation in the form of lifelong monthly income of an amount equivalent to the lowest pension from employment insurance when he/she reaches the general age for retirement, according to the regulations on pension and disability insurance if he/she has not fulfilled the criteria for a retirement pension.

According to the general condition for obtaining the right to the supplement for help and care by other persons, this right is given to a person “who due to physical or sensory damage, intellectual difficulties or changed health conditions needs help and care by another person in order to meet his/her basic living needs”.

In 2015 there was the total of 3,069 children using the basic disability allowance, and 3,656 children using the increased disability allowance (38).

However, the assessment itself is currently based on medical criteria and does not include an assessment of functionality and support needed. In addition, it is more difficult for children with mental and intellectual disabilities to receive this form of support although they need it to the same extent. However, the number of children receiving the increased disability allowance increased by 16 per cent between 2010 and 2015. It is believed that the increased disability allowance is of an adequate level, particularly when considering that the parents of children using the allowance access additional compensation in the form of social pensions. Nevertheless, if we perceive the disability allowance primarily as “compensation for the missed earnings of the parent(s) or as the *service price* for special childcare”, it is recommended to introduce a universal child benefit for children with disabilities (37).

Twenty-six per cent of parents perceive their social status to be poor or very poor, while 58 per cent perceive it to be average.

With regard to housing, 70 per cent of interviewed parents state that they own the property where they live, which helps them reduce living costs. However, because of the prevailing poverty among families with children with disabilities it is important to provide additional accessible housing options. The Law on Housing and Building Maintenance introduces the notion of housing support, but its application is curtailed by the low volume of social housing at local level (39). Housing support is any form of housing assistance provided to any persons who are unable for social, economic or other reasons to provide for their own and their households’ housing needs under market conditions. Those entitled to housing support include persons with disabilities, as well some veterans.

In this respect, this Law does not recognize the families of children with disabilities as a particularly vulnerable group entitled to housing, but it does recognize such families as eligible for assistance with legalization of flats or family houses and/or priority for being allotted housing support.

Partly referring to adequate living standard and social protection, the Committee on the Rights of Persons with Disabilities has expressed concern about the lack of accessible social housing and recommended that Serbia should fully realize the law guaranteeing a quota of 10 per cent accessible flats for persons with disabilities. In order to improve the accessibility of facilities, in 2015 the Rule Book on Technical Standards for Planning, Design and Construction of Facilities was adopted: this stipulates unobstructed movement and access for persons with disabilities, children and elderly persons (40).

Improving the status of children with disabilities requires much more than direct monetary and material benefits: it also involves unobstructed access to services in the area of health and social protection, as well as universal inclusion in the education system (preschool and school).

Right to education

The data collected for this Situation Analysis highlights the weakness of the current education system as well as of the entire society in providing adequate conditions for educating children with disabilities. Although the Republic of Serbia has a strategic direction to develop inclusive education, and the legislative framework ensures free-of-charge primary and secondary education for all children with disabilities as well as unobstructed enrolment in regular schools, children with disabilities are still educated in two parallel systems: regular and special. The most recent legislative amendments restore the possibility of creating special classes for children with disabilities in regular schools. Despite the fact that there are no precise data, it is estimated that in the 2014-2015 school year, about 14,200 children with disabilities attended primary and secondary schools, accounting for 1.7 per cent of pupils. About 6,708 of these attended schools for children with disabilities and about 7,500 were in the regular school system. The data indicate that half of children with disabilities in education attend schools in segregated environments.

It is particularly concerning that parents of children with disabilities perceive children's experience in special schools more positively than in regular schools. Although research shows that schools for children with disabilities do not manage to transfer necessary knowledge and skills for independent life, and employees only think that they are well-prepared for providing support to children in 27 per cent of schools for children with disabilities, parents point out that the education system in such schools is better adapted to children with disabilities than regular education. The positive aspects they emphasize are that in schools for children with disabilities children socialize and develop everyday life skills, there is a larger number of teachers working with the children, and the longer and more flexible working hours mean they can organize in a better way. This result suggests lack of support to those children in regular schools.

Although numerous mechanisms are in place intended to adapt the education process in regular schools for children with disabilities, from accessing school to many other support measures, they have not yet been implemented fully and universally.

For example, lessons can be adapted for children with disabilities who cannot follow lessons in the same way as other children by creating individual education plans (IEPs). This is a way to adapt the syllabus and/or curriculum, results and standards. However, teachers often lack the skills or conditions to apply an IEP, and the teachers themselves tend to hold stereotypes about children with disabilities.

Stereotypes are also prevalent among the general population. According to MICS 2014, only 48 per cent of the population think it is better for children with physical and sensory disabilities to attend regular schools than special schools, while only 32 per cent think this about children with intellectual disabilities. If a child in inclusive education requires additional support, the inter-sector commission for additional educational, health or social support needs, a local self-government unit, assesses the needs for additional support. The commission creates a holistic (comprehensive) support plan for the child but due to its status its conclusions are not binding on service providers. Obtaining the right to support is further complicated by the fact that various types of support, in addition to being financed through different state structures, are also financed from different levels of administration, making coordination very challenging. During 2015 only 173 pedagogical assistants were employed, most of whom worked with Roma children. The same year only 709 children used the services of personal companions to help them get to school and perform everyday activities. These findings indicate that the state as a whole and not just the education system must take urgent measures to support the inclusion of children with disabilities in regular education. The urgency of work to develop inclusive education was also acknowledged by the Committee on the Rights of Persons with Disabilities, which recommended that the Republic of Serbia should no later than 2020 develop an action plan for inclusive education containing specific goals.

In Serbia education is divided into pre-school, primary, secondary, and higher education and adult education.^{14 15}

¹⁴ Legislation also stipulates that classes for students can be organized during treatment at home or in hospital, and provides for distance learning. These forms of learning for children with disabilities are organized at the request of parents or legal representatives.

¹⁵ The education system is managed by the Ministry of Education, Science and Technological Development in line with general principles and goals of education and bringing up children. The Ministry has 16 school administrations (organizational units performing professional-pedagogical supervision, supporting development planning and guaranteeing the quality of work of institutions). Development, monitoring and improvement of education in Serbia are the responsibility of the National Council of Education, the Institute for the Promotion of Education and the Institute for Evaluation of the Quality of Education. For the status of children with disabilities the work of the Group for Social Inclusion of the Ministry of Education is also of great

Pre-school and primary education are compulsory and free of charge for all children in Serbia, including children with disabilities (41). Secondary education is also free of charge for children with disabilities.¹⁶

In the past 10 years important reforms have been made of the education and child development system, and the status of children with disabilities has improved. The greatest progress was made in improving the legal framework and opening up regular education to children with disabilities. While before 2009 not all children were entitled to regular education,¹⁷ the 2009 Law on the Foundations of the Education System (41) and related laws, bylaws and strategic acts (42–51) stipulate the equal right and access to education without discrimination and separation based on any developmental disorders or disabilities¹⁸ (41).

However, both legislative and strategic frameworks still recognize the existence of two parallel education systems for children with disabilities – regular and special. Although the basic strategic direction for the education of children with disabilities is inclusive education, the Strategy stipulates that the transition from special education¹⁹ to inclusive education should take place after all necessary conditions for including the child in the education system have been provided²⁰ (51).

Children may enrol in segregated education on the basis of an opinion from the inter-sector commission for additional educational, health or social support needs assessment and with their parents' consent, if the nature and gravity of the child's disability is such that regular education cannot achieve satisfactory results despite additional support.

importance. The education system is primarily financed from national level, i.e. from the budget of the Republic of Serbia. Funds for education make up 5 per cent of the budget.

¹⁶ Unless they are enrolled in private schools.

¹⁷ Before adoption of the Law on the Foundations of the Education System from 2009, the Commission for the examination of children with disabilities established whether child had the capability for education and training and determined the type of school the child would enrol in, according to the 1986 Decision on the criteria for categorizing children with disabilities and the method of work of the Commissions for the examination of children with special needs, regardless of the parents' attitudes and wishes.

¹⁸ Including also children accommodated in social protection institutions, sick children as well as children undergoing hospital and house treatment.

¹⁹ Education in child development and education institutions and programmes.

²⁰ Ensuring additional funding, preparation of institutions and special help to those institutions with a larger number of students with disabilities, staff training, providing adapted spatial and other conditions, development of adequate programmes (including individual education plans), resources for learning and technical aids, providing special support systems (including personal/pedagogical assistance as well).

Although the opinion of the inter-sector commission itself is not binding and the choice of institution depends on the child's parents, having two parallel education systems for children with disabilities does not comply with the international legal framework.

The Law on Pre-School Education does not make mention of separate institutions for children with disabilities. Children with disabilities may exercise their right to pre-school education with all other children in an educational group, based on individualized plans or individual education plans.²¹ ²² According to amendments to the Law in 2017, child enrolled in "developmental" groups (small segregated groups of children with disabilities) should enjoy everyday interaction and inclusion in the activities of regular "educational" groups. During the pre-school programme the child's development is also monitored as proposed by the team for inclusive education so that the child with disabilities can transfer from the developmental to the educational group. With regard to primary and secondary education, the Law on the Foundations of the Education System, besides covering enrolment at primary school,²³ also stipulates that children with disabilities have the possibility of enrolling at schools that educates pupils with disabilities.

Despite the fact that Law on Primary Education and Upbringing from 2013 revoked special classes for children with disabilities at primary schools, amendments to this Law in 2017 allow special classes to be created for children with disabilities as a form of streaming.

²¹ Although it is not stipulated in the Law, there are also pre-school groups in schools for children with disabilities: children with disabilities can all attend compulsory pre-school programmes at these schools.

²² There can be up to two children with disabilities in one educational group. The number of children in an educational group is reduced by three for every child who is entitled to additional support and an individualization plan or an individual education plan.

²³ The first grade of primary school is compulsory for all children between 6.5 and 7.5 years of age before the beginning of the school year. Instead of checking their readiness for starting school, testing is only conducted after the child's enrolment and only to establish whether the child needs additional support to achieve better results in regular schooling. International standards²³ and recommendations of international treaty bodies emphasize the state's obligation to ensure the right to inclusive education for every child with disabilities, but articulate this it does not mean maintaining a parallel special education system. However, Serbia's strategic direction until 2020 is to keep special schools for "specific circumstances and those categories of children who still need them, while other such schools should be converted into resource centres to provide help to regular schools, teachers and families in applying an inclusive approach in schools in the municipality or region".

In order to ensure that the educational process is adapted to children with disabilities, numerous support mechanisms and various adaptations of the educational process are in place.

The principal bodies responsible for equalizing educational opportunities for children with disabilities are:

- The expert team for inclusive education;
- The team for providing additional support to a child/student; and
- The inter-sector commission for additional educational, health or social support needs assessment of the child and student (hereafter inter-sector commission/ISC)

Team for inclusive education

In order to provide support for the education of children with disabilities, it is stipulated that all pre-school institutions, primary and secondary schools should set up expert inclusive education teams tasked with working to develop and improve inclusion climate, policy and practice at institutional level. This team devises measures to implement inclusive education in schools and mechanisms for full inclusion of children, applies anti-discrimination measures and develops teachers' competences for inclusive education. The team works to identify children from vulnerable groups in a timely manner, facilitates the participation of parents and ensures cooperation between teachers and parents to support children.

Team for providing additional support to a child/student

If there is a need for additional educational support, a team is set up to provide this support. It is composed of the parent, an educator/teacher, or the class teacher and expert associate, as well as – depending on the child's needs – the pedagogical assistant or the companion providing personal assistance to the child, if proposed by the parent or guardian. The team monitors the child's welfare and progress in development and learning, and creates a pedagogical profile of the child as the basis for planning support and adaptation in the educational process through the individualized plan and/or the individual educational plan, with the adapted or modified programme.

Inter-Sector Commission

The Inter-Sector Commission (ISC) is a body at local self-government level composed of permanent representatives of the education, social protection and healthcare systems (a paediatrician, a social centre representative, a “defectologist”²⁴ with a relevant profile and a psychologist employed in the education system).

The Commission also engages temporary members, who are persons who know the children/students well and have had a longer-standing contact with them. A temporary member is selected for each child/student individually.

The basic role of the ISC is to assess the child’s needs for additional support, i.e. rights and services to enable the child to overcome physical and social barriers to be able to perform everyday activities important for inclusion in education, community life and development in an unhindered manner. Each child who, due to social deprivation, disabilities, learning difficulties or any other reasons, requires additional support to develop and be included in education and community with fewer difficulties is entitled to such support. Based on its assessment of the child’s needs for support, the ISC issues a written opinion including the following: the child’s personal data; data of the ISC members; the place of the assessment; the assessment methodology; a description of the child and the circumstances in which the child and his/her parents live; identified barriers (social, medical, educational and community) encountered by the child; an individual support plan for the child setting out rights and services in the healthcare system, social protection system and education system; an additional support needs assessment for the child; the type of additional support the child needs and how it may help the child overcome barriers, including coordinated inter-sector cooperation; the timeframe in which additional support measures will be implemented; and the place where additional support will be provided. Thus, the basic role of the ISCs is to state the measures required to provide holistic support for the child to ensure his/her equal participation with other children in education.²⁵

Although the ISCs are designed primarily to provide support in education, they are an important mechanism for coordinating services to facilitate social inclusion for the child at local level. Apart from the assistance provided to children by personal companions, an institution may also engage pedagogical assistants to support children with disabilities in

²⁴ A professional profile that still exists in the Serbian system

²⁵ One of the most important forms of support is the pedagogical assistant’s service, which should be available within pre-school institutions and primary schools. The assistant provides support to children, but also to educators, teachers and expert associates to improve work with children and facilitate cooperation with parents.

the learning process. However, this position is not clearly defined and there are no prescribed criteria for engaging pedagogical assistants (52).

Meanwhile, it should be taken into account that the personal companion is a social protection service and he/she can only offer support to the child in the education process: it is up to schoolteachers themselves to adapt the education process itself to each child with a disability.

The most important mechanisms for improving the position of children with disabilities are:

- Drawing up individualization plans;
- Drawing up individual educational plans with adapted programmes;
- Drawing up individual educational plans with modified/reduced content, outcomes and standards; and
- Adjusting the number of students in an educational group/class.²⁶

The initial support for children not realizing the expected educational achievements is provided by differentiated and individualized teaching and extracurricular activities. If this does not result in improvement in the child's achievements, then an individual education plan is drawn up with the adapted programme (adaptation of methods, materials, space and conditions) according to which the educational/development process for that child/student will be performed (hereinafter IEP1). The expert team for inclusive education makes a proposal for drawing up the individual educational plan and the team for providing support to the child/student then implements this. If the support measures stipulated in the IEP1 document are unsuccessful, the team supporting the child, with the parents' consent and the agreement of the ISC, draws up an individual educational plan with modified/reduced content, outcomes and standards (hereinafter IEP2).

Although the legal framework prescribes numerous types of support for children with disabilities to ensure their inclusion in regular education, continuing the parallel education system for children with disabilities does not, however, comply with the international legal framework.

²⁶ At the pre-school level there are additional conditions for adjusting the number of children in educational groups depending on whether or not children with disabilities also attend. In one educational group there cannot be more than two children with disabilities, while the maximum number of children in an educational group with one child with a disability is three less than otherwise. Meanwhile, the number of children with disabilities who can be enrolled in developmental groups is between four and six.

Inclusion of children with disabilities (like other children) within pre-school education is low. However, there are no adequate disaggregated data on disabilities. In 2011, 39 per cent of children in the age group were in pre-school education and ²⁷ (53), with lower figures in rural regions (29 per cent), and for children living in residential institutions (13 per cent) (54, 55). Inclusion is particularly low for children in crèche programmes (up to three years of age), standing at 16 per cent (53).

Similarly, only 50 per cent of children between three and five years of age are enrolled in the pre-school education and care programme, and only 4 to 10 per cent of these children come from vulnerable groups (27). Although it is estimated that 5 per cent of children in Serbia have disabilities, only 1.2 per cent of the enrolled children had disabilities (56), suggesting that children with disabilities have four times less opportunity to attend pre-school at this age. The total number of children with disabilities who attend kindergartens is unknown. Although there are no separate pre-school institutions for children with disabilities, data show that in 2016-2017 there were 50 developmental groups for children with disabilities attended by 394 children, while individual education plans were created for 759 children attending pre-school programme and pedagogical profiles was created for 1,513 children. Inclusion is much better in the compulsory pre-school programme: in 2014 65,491 children were enrolled in the preparatory pre-school programme, an inclusion rate of 94 per cent of all children in the age group. According to 2011 data, there were 159 state-owned and 60 private pre-school institutions in Serbia at that time (57).

At primary and secondary education levels in Serbia there is a network of 3,413 regular primary and regular secondary schools, as well as 211 special primary schools and classes for schoolchildren with disabilities and 42 special secondary schools for students with disabilities. Special schools are created for certain types of disabilities and are not uniformly distributed but concentrated in large cities.

A total of 813,219 schoolchildren and students attended regular primary and secondary in 2014-2015, of whom 555,573 (68.3 per cent) attended primary school and 257,646 (31.7 per cent) secondary school. In the 2014-2015 academic year 6,708 children were enrolled at special schools, of whom 37.9 per cent were girls.

²⁷ Twice lower than EU level.

A total of 4,768 children with disabilities attended special primary schools, of whom 38 per cent girls, and 1,940 attended special secondary schools, of whom 37 per cent were girls.²⁸ This means that 0.9 per cent of primary schoolchildren were in the segregated education system and 0.8 per cent of secondary school students.

During 2014-2015 8,882 children attending regular schooling had individual education plans: of whom 5,237 children (38 per cent girls) followed IEP1, and 3,645 children (40 per cent) girls IEP2.²⁹

ISC opinions were issued to 3,834 children, of whom 39 per cent were girls. Of these, the schools initiated the procedure with the ISC in 69 per cent of cases.

Neither the number of IEPs nor the number of children ISC opinions reflects the number of children with disabilities. However, it is expected that the number is somewhere between the two. Specifically, some children with IEP do not have ISC opinions, and not all children with IEPs are necessarily children with disabilities. Nevertheless, in the 2014-2015 school year, 84 per cent of children with IEPs had been placed in category A (children with disabilities).

Every tenth child with an IEP was categorized with learning difficulties (Category B), while 6 per cent were children from socially and economically deprived environments (Category C).

It may thus be concluded that in 2014-2015 about 7,500 children with disabilities attended regular primary schools, accounting for 1.3 per cent of all children in regular primary schools.

There were 595 primary school classes for children with disabilities in special schools, making about 8 schoolchildren per class. At secondary schools there were 341 classes, or about six children with disabilities per class.

Special primary schools are attended mainly by children with "mental retardation" (68.0 per cent) and children with multiple disabilities (20.1 per cent). Schoolchildren with impaired vision or hearing account for 11.4 per cent while schoolchildren with physical disabilities account for only 0.2 per cent. The proportions are similar at secondary level: 58.3 per cent have "mental retardation", 16.4 per cent multiple disabilities, 20.8 per cent impaired vision or hearing, and 4.5 per cent physical disabilities.

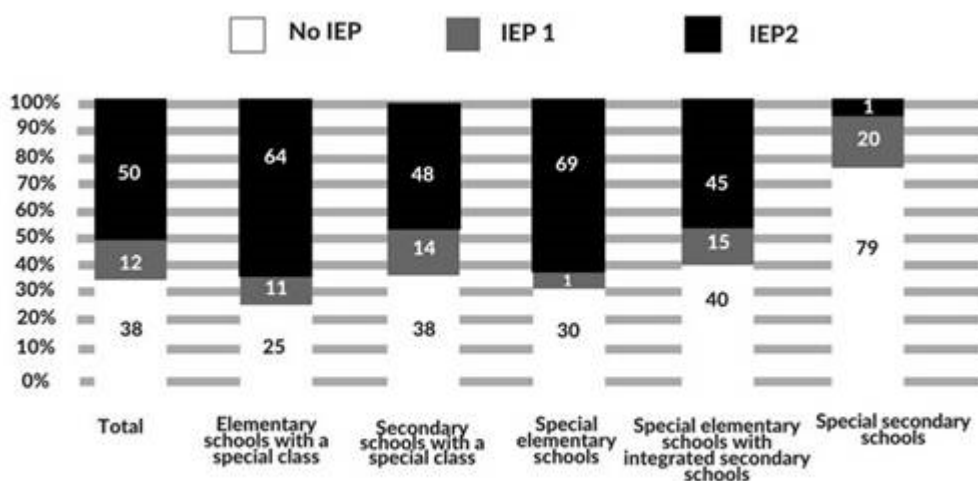
²⁸ The number of schoolchildren with disabilities attending special schools practically remained the same in 2015-2016.

²⁹ During the 2016/17 academic year the number of IEPs increased: 8,073 children at primary schools were educated under IEP1, and 4,881 under IEP2.

A total of 62 per cent pupils in special education had IEPs: 50 per cent had IEP2, and 12 per cent IEP1. In other words, over 80% per cent that have educational plan have IOP2.

As shown in Figure 5, a total of 62 per cent pupils in special education had IEPs: 50 per cent had IEP2, and 12 per cent IEP1. In other words, over 80% per cent of children that have educational plan had IOP2.

Figure 5. Percentage of schoolchildren who had individual educational plans in special schools and classes for children with disabilities in the 2014-2015 school year



The ratio of children with IOP2 and IOP1 in regular schools is somewhat different. Only 41 per cent of children with an educational plan in regular classes have IOP2 (58). This indicates that most children with disabilities attending regular schools have mild and moderate disabilities, while children with multiple and serious disabilities are more likely to be educated in segregated educational systems.

These data indicate that in the 2014-2015 academic year about 12,300 children with disabilities attended primary schools, of whom, 60 per cent were in regular schools and 40 per cent in segregated setting. The survey of parents for the Situation Analysis had a similar finding, that 58 per cent of children with disabilities who enrolled at school in the 2014-2015 academic year or later enrolled in regular schools, and 42 per cent enrolled at special schools for children with disabilities.

In total, 14,200 children with disabilities were included in primary or secondary education, which is 1.7 per cent of all children attending primary and secondary schools.

If the same estimate is accepted that 5 per cent of children have disabilities, it can be concluded that only 34 per cent of children with disabilities are being educated.³⁰

These data indicate that a large number of children with disabilities are still being educated in special schools, but there is an encouraging trend of falling enrolment. In the 2014-2015 school year 13.9 per cent fewer children were enrolled in special schools than in 2009-2010, while the total number of children enrolling in regular schools in the same period fell by 4.8 per cent, and there was a 25.3 per cent fall in the number of children in special classes in primary schools. In the same period the number of children with disabilities in primary schools increased by 49.6 per cent (58). The increasing inclusion of children with disabilities in primary education is supported by the fact that 94.0 per cent of parents of children with disabilities between seven and 12 years of age tried to enroll their children at primary schools, while 73.8 per cent of parents of children between 16 and 17 years of age tried to do the same. Of those schoolchildren who changed their status more transferred from regular to special schools or special classes than from special to regular schools. Less than 1 per cent of schoolchildren transferred from special to regular education, while a little more than 4 per cent transferred from regular schools to a special school or special class (58). In the same period there was no substantial reduction in the number of children with disabilities enrolling at secondary schools for children with disabilities: enrolment fell by 6.7 per cent in secondary schools for children with disabilities compared to a 9.0 per cent fall recorded in the general population.

A total of 48 per cent citizens think that it is better for children with physical and sensory disabilities to attend regular rather than special schools, while 32 per cent think the same about children with intellectual disabilities.

However, as many as 76 per cent of respondents think that children with physical and sensory disabilities who attend regular schools have a negative effect on other students, while 65 per cent think the same about children with intellectual disabilities (27).

Although numerous measures have been introduced to assist children with disabilities to enter the regular education system under equivalent conditions, these support systems still do not function well enough to enable children with disabilities to enjoy education equally with other children.

³⁰ Children with disabilities can be included in education without being identified as such and thus this is only a conservative estimate.

“Monitoring and Evaluation of the Situation in Inclusive Education in the Republic of Serbia” research from 2016 indicates that 1.7 per cent of parents were aware of discrimination in enrolment (58). However, as many as 27 per cent of the parents who participated in the Situation Analysis survey reported difficulties enrolling their children in primary schools: these were frequently mostly parents of children with intellectual difficulties and mental disabilities (34,7 per cent).

“They talked to me; no, I talked and they listened to me. I came prepared and told them that they couldn’t turn me down.”

Mother of a child with disabilities

“I think that my child was discriminated against at that moment because we had applied for the regular kindergarten previously. After that conversation they saw what my child looked like, I know it sounds terrible to say, they realized the type of hyperactivity and how hard it was. Then he wasn’t enrolled although he had a legal right to be. They said that they already had some children with disabilities and could take no more. My husband is a legal adviser and we threatened to sue them and banged our fists on the table. My son was enrolled after the registration period. Afterwards they said that they thought we didn’t really want to enroll the child in the kindergarten but had applied just for the sake of it, as if it were our hobby to apply in response to different advertisements.”

Mother of a child with disabilities

Restricted opportunities for children with disabilities to attend schools are not affected only by discrimination in the registration process, but also by the fact that most schools are not accessible to all children with disabilities.

“My son used to go to a regular school and the only problem we had was accessibility. My son attended the only primary school that offered us the opportunity to construct the ramp at our own expense. On the other hand, the only secondary school accessible to someone in a wheelchair was the economics school. He wasn’t able to choose so he had to go to the economics school.”

Father of a child with disabilities

The survey results indicate that the most common difficulty parents had in enrolling their children was the belief of staff members that they were not competent enough to work with such children and that the children would be better off in other schools (72.0 per cent). About a fifth (22.2 per cent) of parents who tried to enroll their children could not do so in the first primary school they came to, while 7.0 per cent failed to enroll their

children at all. These data show that many parents of children with disabilities still face barriers to enrolling children.

In the families participating in the survey, about 3 per cent of children with disabilities stopped going to school. Parents in focus groups organized for the Situation Analysis spoke about their experiences which, in their opinion, revealed indirect encouragement of children with disabilities to leave regular schooling.

“And that really looks like an attempt to expel the child. I can recognize it exactly. For example, when he ran and screamed with joy during the school break, the teacher in charge says he was disastrous and fighting with the assistant. And right there there were three children openly fighting, but only my child was being watched.”

Mother of a child with disabilities

“But I also had a problem with the educators there. They would wait for me at the door and start making different comments to me. I asked them if they wanted me to take him home. They didn’t know what to answer. They just shrugged their shoulders.”

Mother of a child with disabilities

Various studies show that parents/guardians are not always actively included in the process of planning and creating IEPs for their children. They frequently only see the document when those in charge want their signatures. This attitude to parents may lead to additional resistance and an atmosphere of non-cooperation. Some other reasons have been identified why parents do not give their consent for IEP production, for example not being informed, connecting IEPs with special schools, prejudice about their children being stigmatized, being ashamed because their children are different from others, concern that their children will be isolated and rejected by the environment, fear of their children being discriminated against, and lack of understanding of the advantages of working to an IEP (59).

Nevertheless, the parents who participated in the Situation Analysis survey were generally pleased with the process of adjusting teaching in regular schools to schoolchildren with disabilities, as well as the IEP production process itself.

In that respect, 89 per cent parents of the children for whom IEP was produced are pleased with their children’s progress.

“He started the fifth grade and the psychologist monitored my son all the time. I liked that. She was absolutely involved in his story from the very first day. He started his fifth grade following the IEP because he was already in the wheelchair. His PE teacher did all he could. He chose exercises just for him and gave him some special tests... He was completely involved in everything.”

Mother of a child with disabilities

The same attitude is taken by teachers, 77 per cent of whom stated that children with IEPs made progress. However, only 12 per cent of pupils with disabilities in regular secondary schools and 23 per cent those in special secondary schools made progress (58). However, the impact of IEP on children’s education has not yet been assessed so the effects of following IEPs are not known.

All stakeholders generally agree that children with disabilities have insufficient support available to participate in regular education and develop their skills and talents. This refers support within school, from pedagogical assistants, as well as support services to develop the children’s skills (such as speech therapy) and services important for children’s participation in the community, such as the service of a personal companion.

“We wanted to move away, seriously. I travel 10 km to reach the nearest speech therapist. It is very hard for them in the kindergarten.”

Mother of a child with disabilities

Apart from the insufficient number of pedagogical assistants, studies also show that most of them do not have enough knowledge and skills to meet the requirements and offer all the support needed by children with disabilities (52).

When considering the possibility of adjusting school teaching for children with disabilities it is particularly important to mention the adoption of the Law on Textbooks (45), which stipulates that textbooks should be adjusted so that schoolchildren with disabilities can use them with content and/or format adjusted to their abilities, needs and potential. However, civil society organizations and parents emphasize that textbooks and supplementary materials are not adjusted sufficiently or at all to the needs of children with disabilities, especially children with impaired vision.

In the 2017-2018 academic year, the Ministry of Education, Science and Technological Development provided textbooks adapted for children with disabilities who are following IEP, based on the information submitted by schools.

Information from the Ministry of Education, Science and Technological Development suggests that limited support is provided. In August 2015 the job of pedagogical assistant was performed by 173 employed associates (52). The educational attainment of the plurality (45 per cent) was completing secondary school, while 78 per cent spoke the Romani language.

This leads to the conclusion, although there are no accurate data, that most pedagogical assistants were engaged to work with Roma children, and even if they had worked with children with disabilities, the total number of pedagogical assistants would have covered about 2 per cent of children with disabilities in the education system.³¹

The personal companion service is available in 30 of 174 local self-government areas and had 709 users in 2015, but not throughout the entire school year.

“He didn’t fit in; poor working conditions and no personal assistant. The educators were simply unable to work with my child. I can’t say that they weren’t willing. Other children wanted to socialize with my child but weren’t able to. My child also wanted to socialize with them. In the end my child was transferred to a school for children with impaired hearing. It was such a relief.”

Mother of a child with disabilities

“When he started the first grade, his grandfather stayed in the classroom with him because I had to work. He sat in the back, as agreed, which means that he didn’t interrupt the class. He wrote and did everything on his own. Later on, when alternative civilian service was established, we managed to organize everything. That was the first ‘plainclothes soldier’ who became a personal assistant to my S. That is how we organized things.»

Mother of a child with disabilities

“We would like our children to have assistants at school, but it is just wishful thinking.”

Father of a child with disabilities

A significant challenge to establishing a support system is inconsistency in the method of work of ISC and insufficiently-developed support services and support mechanisms. The assessment method applied by ISC differs depending on the local community, while

³¹ In practice, pedagogical assistants and personal companions are often confused for each other. While pedagogical assistants are financed by the education system and have the basic function of providing support to children to learn in the school environment, personal companions are employed by social protection services and their main function is to support children’s participation in the community.

communities also differ by how well support services for children are developed and by availability of support. This leads to regional differences in access to education. This is understandable bearing in mind that most ISC members who were trained for the role considered the training generally useful but that it did not give enough information about the child evaluation and types of direct support (57).

Thus, the ISC members stated that they do not clearly understand the difference between some forms of support, such as pedagogical assistants and personal companions (57). Moreover, basic material conditions for the work of ISC are most often not in place, payments for ISC members vary depending on the local authority, and there is no template terms of reference, rules of procedure or other internal documents regulating ISC work (57). There is some evidence³² that some ISCs do not follow the legal framework, are late in giving opinions, and only give opinions confirming the request of the parents and school without making comprehensive assessment of the child's support needs; that assessments are not made in the child's natural environment as should be the case but in municipality offices; and that the procedure does not include temporary members who are most familiar with and aware of the child's functioning. Children participate in the assessment process very rarely or only to a limited degree (57).

However, the biggest barriers are to realizing the services and support recommended in the ISC opinion. As the opinion is not binding, in practice services are often not financed and provided. The most significant concern raised by child rights organizations regarding the functioning of these commissions is the fact that local government often has insufficient funds to finance the measures the commissions prescribe (60).

The ISC also has no competence to monitor implementation of the measures, so parents are left completely to themselves to implement the support measures prescribed.

Faced with the lack of support services, some commissions have established the practice of directing parents only to measures which exist in their communities, but which are not sufficient to ensure the child's educational inclusion (57). In recent years several objections to the work of the ISCs were filed to the Ombudsman, and several others to the Commission for the Protection from Discrimination in relation to failure to implement the support that the ISC mandated.

³² See also, e.g. Miražić-Nemet, D., Stefanović, S., *Guidelines for planning and providing adequate inter-sector support for inclusive education in a local community (practical policy proposal)*, MODS 2015, "Framework for monitoring inclusive education in Serbia", Institute of Psychology at the Faculty of Philosophy in Belgrade, 2014; Vlaović-Vasiljević, D. et al, *Guide to the work of inter-sector commissions (ISC) for additional educational, health or social support needs assessment of the child and student*, Centre for Social Policy, 2016.

Although special schools for children with disabilities are envisaged as resource centres for regular schools (58), respondents from almost half of these schools stated that it was necessary to improve their accessibility, provide support for children through personal companions and acquire adapted textbooks. Only 27 per cent of the schools believed that they were well prepared to support the additional needs of their students while 38 per cent thought they are very poorly or poorly equipped (58).

The representatives of special schools for children with disabilities stated that the staff they particularly lacked were oligophrenologists (36 per cent), “defectologists” (29 per cent), speech therapists (24 per cent), nurses/physiotherapists (13 per cent) and pedagogical assistants (10 per cent) (57). These concerns may imply that employees continue to perceive children with disabilities through a medical model. (58).

In recent years schools have been mobilized to make progress in all aspects of ensuring equality in education, including the acquisition of assistive technologies (AT). However educational institutions have been found to lack adequate assistive technologies, and existing information and communication technologies (ICT) are rarely used as assistive technology (58). Establishing resource centres for assistive technology would lead to the networking of experts and enable them to use their time and knowledge far more efficiently, and to make their advice more available to children, parents, educators, expert associates and ISC members, as well as healthcare and social workers who deal with children with disabilities. In this context, the Ministry of Education, Science and Technological Development has published a “Catalogue of Assistive Technology”, which has educational content and provides an overview of assistive technology instruments and devices, including their basic characteristics and purposes. The Catalogue was created in line with the universal design principle (61).

Insufficient adjustment of schools for educating children with disabilities is also proved by the following quote:

“I have already told you that in my daughter’s school, which is a school for children with impaired hearing, teachers don’t know sign language, and so the children just go to school as a formality. This must be changed immediately.”

Mother of a child with disabilities

Nevertheless, most participants at the focus groups think that special schools for children with disabilities offer better educational conditions for children with disabilities.

“He likes being with other children at a special school. For example, there are children who don’t walk. He feels good when he comes here because he can see that there are other children with disabilities. In the place where we live there are no other children in wheelchairs and he doesn’t want to be with other children so he spends all his time with me.”

Mother of a child with disabilities

“My child went to a regular school and then moved to a special school for children with disabilities. I think that he is doing much better in the special school. There are children like him at the school. He looks forward to going to school. He gets angry when I tell him that he doesn’t have to go to school on Friday and he can have a long weekend. This school seems to be better for parents too as I had to stay with my child in the primary school because, though they have the permission to take in children with disabilities, in practice it is completely different. I couldn’t use the toilet and there were no employees who could help my child. Here I don’t have to be at school all the time and I am definitely less busy.”

Father of a child with disabilities

Educational reforms in Serbia directed at deinstitutionalization and including more children with disabilities in regular schools have started having an effect. Changes include a reduction in the number of children in special schools, preventing an unreasonably large number of Roma children from entering these institutions, and including children with serious and multiple disabilities who were outside the system in the schools. Meanwhile, a number of “defectologists” employed in special schools have obtained new professional roles providing support to children and students with disabilities who attend regular schools.

Although the legal framework stipulates cooperation among schools, regular schools do not use their resources for children with disabilities to a large extent. Less than a third of schools (29 per cent) stated that their teachers were providing additional support to other classes or schools.

Only 11 per cent of teachers offer additional help to other schools and classes (58). It is not clear if special schools for children with disabilities can actually function as resource centres for regular schools both because of the way they are equipped and adapted, and due to their geographical distribution, which is rather uneven.³³

“Quantitative and qualitative analysis of teachers’ competences for inclusive education show that the largest requirements for professional specialization are for knowledge about developmental characteristics of children with disabilities; production and implementation of IEPs; monitoring, evaluation and grading of schoolchildren; teaching methods; and general skills. There is also an emphasis on sensitivity for an inclusive approach to education and cooperation with parents.” (62)

A secondary data review of what teachers need to implement inclusive education shows that teachers are ready to adapt and implement inclusive education, but think that they lack knowledge, information and competences about inclusive education and potential benefits (63, 64). However, some teachers still think that children with disabilities should not attend regular schools and that they “put pressure on healthy children” (57). Teachers who had been involved in various projects on this issue even before the clear legal definition of inclusive education are more willing to accept schoolchildren with disabilities and have a more positive attitude towards them (65). It also transpires that teachers having personal experience of persons with disabilities also has a positive effect on their attitude.

The extent to which teachers are sufficiently competent to work with children with disabilities is under question. Teachers frequently just let children with disabilities pass by, allowing them to move up a grade without acquiring the necessary knowledge.

“The teacher used to let him pass. I was not pleased. He came home without workbooks. I went to complain about it and see what was happening. She always told me that he was a good and quiet child, just sitting and drawing. I asked her if she could sometimes give him a bad mark. ‘A bad mark, but why?’ My answer was that I wanted him to start doing something.

³³ In order to improve the availability of support to schools, amendments to the Law on the Foundations of the Education System stipulate that regular schools with pupils with disabilities should also provide support to other schools as well as the children’s families.

When he came home I asked him about homework, but he never had any. The same happened in the second grade and then I requested his transfer to a school for children with disabilities. There he achieved incredible success. The things he learned were good for him.”

Mother of a child with disabilities

Development of competences of schoolchildren with disabilities is not only important for regular schools but also for special schools. At the focus groups for the Situation Analysis parents mostly focused on development of skills for independent living and, to a lesser extent, adopting knowledge and skills as defined by the school programme per school programme. Research by IPSOS Strategic Marketing reveals a failure of special schools to pass knowledge to children with disabilities and inability to help the children develop the skills necessary for independent living (58).

In 2010 the Network for Support to Inclusive Education³⁴ was established to support educational and care institutions to develop and implement inclusive education. The Network consists of more than 120 practitioners (educators, teachers, psychologists, pedagogies and other experts) in the regions who, in cooperation with educational advisers, provide direct support to schools and parents through school visits, instructions about working methods, proposals of support measures, supervision and monitoring.

In addition, the Network regularly organizes trainings for education professionals on inclusive education, and analyses and assesses the functioning of various mechanisms to support children from vulnerable groups.

The Ministry of Education has commissioned analysis of schools' needs for assistive technologies to work with blind and visually impaired pupils. It is intended that information will be provided about the aids and assistive technologies necessary for the education and care of these children.

³⁴ For more about the Network for Support to Inclusive Education see:
<http://www.mrezainkluzija.org/>

Insufficiently developed procedures and insufficient funds allocated for providing support for inclusive education at local level often aggravate provision of services that require additional financing. This has been recognized as a problem that must be urgently resolved by developing more efficient mechanisms of inter-sector cooperation.

Vulnerable children are most at risk of being excluded from education. During 2015, 74 per cent of those living in residential institutions for children without parental care were being taught (pre-school, primary and secondary). A plurality attended special primary schools (28.3 per cent) and special secondary schools (11 per cent), with 18 per cent at regular primary schools and 15.2 per cent at regular secondary schools.³⁵

As many as 61.2 per cent of schoolchildren in institutions for children and youth with disabilities are not being taught in the education system. The staff of residential institutions for children with disabilities believe the largest barriers to the children's education to be insufficient finances, especially to transport children and personal companions, while special schools state that they require support from assistive technology, teaching materials and additional financial funds. In-depth analysis reveals that the difficulties and barriers preventing children in institutions learning in the education system can be placed into two basic categories: 1) attitudinal barriers, or the medical model of understanding children's needs and orientation to the needs of the institution, and rather than to the needs and rights of children, and 2) organizational barriers, such as the need for additional support to children with disabilities and lack of cooperation among vital actors for children's development (66).

Therefore children in accommodation are placed in a still more difficult position; they are segregated and isolated and suffer institutional discrimination.

Thus, while it may be concluded that the state has undertaken many measures to make education available to children with disabilities, results are still missing, especially when considering particularly vulnerable groups of children with disabilities.

³⁵ Report on the work of institutions for accommodation of children and youth for 2015, Republic Institute for Social Protection, Belgrade, 2016.

The Committee on the Rights of Persons with Disabilities has also drawn attention to the insufficient effectiveness of education for children with disabilities, and has recommended Serbia to “identify concrete goals in the Action Plan for inclusive education (2016-2020) to meet inclusive education standards and requirements. Special attention should be given to children with multiple disabilities, and pupils and students with disabilities living in institutions, as well as to the development of individual education plans and accommodation of all types of disabilities”. In the European Commission’s 2016 Progress Report for Serbia, special emphasis is placed on the insufficient availability of education for children with disabilities in large residential institutions. The Committee on the Rights of Persons with Disabilities has expressed its concern that Serbia has no strategy to ensure accessibility, which leads to insufficient availability of good-quality pre-school, primary, secondary and tertiary education for persons with disabilities. A lack of reasonable adaptation for children with disabilities in line with individualization plans, or IEPs has also been identified.

Social protection and life in the family

Environment

The social protection legislative framework offers a good basis for developing comprehensive support for children with disabilities and their families. The system itself is largely decentralized, and responsibility for developing community services has been devolved to local self-government level, ensuring better adjustment of community services to citizens' needs. However, the legislative framework does not stipulate any specific funds for financing such services and there is no obligation on local self-governments, so from a structural perspective, community services are not sufficiently sustainable and comprehensive. Furthermore, the criteria currently defining standards for community service providers make service provision by civil society organizations and development of innovative and flexible services more generally harder. This leads to insufficient and uneven service development at local level. In other words, in general services supporting children with disabilities to live with their families are unavailable. In 2015 home assistance was only provided to children in 14 per cent of local self-government areas, and day accommodation in 47 per cent, while personal companions were available in 21 per cent of areas and respite accommodation in 6 per cent. Because of the relatively low availability of support in the social protection system, families tend to rely on extended families (44 per cent) and neighbours (16 per cent) for support with care. Parents believe they are most frequently left to themselves and rely more on themselves and informal sources of support than on social protection services. The introduction of specific-purpose transfers in 2016 has great potential for developing community services: a total of 400 million dinars (US\$ 4.2 million) were distributed to local self-governments through this mechanism in 2016 and 700 million dinars (US\$ 7.3 million) in 2017.

Apart from the insufficient development of community services, reform of the social protection system and the moratorium until the end of 2018 on recruiting new staff in the public sector have had particularly negative impacts on centres for social work. The number of social protection workers dealing directly with users has fallen while the reform has increased the workload on the administration, which together with the increased number of users makes it more difficult to recognize the needs of children with disabilities and their families in the community in a timely fashion, provide adequate services and coordinate with other service providers.

All this means that the right to family life is still less available to children with disabilities than to other children. Children with disabilities are overrepresented in non-family care – accounting for 22 per cent of all children in social protection institutions and foster families, four times more than the assumed 5 per cent in the general population.

At the same time, children with disabilities account for over 70 per cent of all children in residential institutions and only 14.3 per cent in foster care.

Children are still accommodated in large residential institutions with adults, which leads to significant risks to the children’s welfare.

The fact that the healthcare system sends newborn children to these institutions is a particular challenge. However, it should be noted that the number of children residing in institutions fell from 1,265 in 2010 to 716 in 2016. Nevertheless, given the lack of reliable statistics on the number of children with disabilities in communities, uneven availability of community services and non-timely recognition of children who need support, this raises the question of how many children with disabilities actually live in the community without support and are at risk of neglect.

The national legal framework defines social protection as “organized social activity in the public interest to provide assistance and application of independent and productive lives in society for individuals and families, and to prevent the consequences of social exclusion” (36). The Law on Social Protection recognizes the prohibition of discrimination – on the basis of, among other things, disability, age, and the nature of social exclusion – as one of the fundamental principles of social protection.

Total expenditures on social protection:

Serbia: 23.3 per cent of GDP

EU: 28.6 per cent of GDP

According to the Law on Social Protection, a child can use the rights or services of social protection if his/her family and other life circumstances endanger his/her health, safety and

development: that is if it is certain that without support from the social protection system he/she cannot achieve an optimum level of development, and in particular if he/she has developmental disorders or disabilities, while his/her care and material safety needs exceed the family’s capacity (36).

Social protection services include assessment and planning services, everyday community services,³⁶ support services for independent life,³⁷ advisory-therapeutic and social-educational services (which also involve intensive support services for the family) as well as accommodation services.

Social protection services are provided to citizens through a network of social welfare centres established by local self-government units, and through a network of service providers that may include both public institutions and private organizations.³⁸

In addition, the budget of the Republic of Serbia finances alternative care services,³⁹ and also most of the costs of social welfare centres, while community services are financed locally, but without mechanisms to ensure their sustainability and availability depending on needs.

The Employment and Social Reform Programme (ESRP) sets as one of the most important tasks increased support to the natural family *with the aim of preventing the separation of children, continuation of the de-institutionalization process and development of services in the community*. The largest challenges identified by the ESRP in this field are *the strengthening of mechanisms and programmes to support the natural family* (expanding services in the community, particularly those supporting inclusion in the regular education system), and *further development of family accommodation for children with disabilities*.

³⁶ The Law on Social Protection recognizes the following everyday community services: day care centres, home help, shelters and other services supporting users in their families and immediate environment.

³⁷ The Law on Social Protection recognizes the following as support services for independent life: accommodation with support, personal assistance, training for independent life and other types of support necessary for active participation of users in the society.

³⁸ Key actors in the development and implementation of social protection in Serbia are the Ministry of Labour, Employment, Veteran and Social Affairs which includes the Sector for Care about Family and Social Protection and the Sector for Protection of Persons with Disabilities, the Republic and Regional Institutes for Social Protection (monitoring and improvement of the general concept and practice of social protection, encouragement of development, research in the area of social protection).

³⁹ Institutions for children and young people which offer services of residential accommodation and centres for family accommodation and adoption which offer foster care services.

Under international conventions, the basic role of social protection is to guarantee the child the right to a safe and supportive life in his/her family, or to ensure regular maintenance of personal and direct contacts with both parents if the child does not live with them (23).

Furthermore, the Convention on the Rights of Persons with Disabilities emphasizes that children with disabilities have equal rights regarding family life, that they cannot be separated from their parents against their free will, and that in no case can they be separated on the basis of a disability (2). Both the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities prescribe that states are obliged to provide children and their families with comprehensive information, services and support with raising children to ensure that children can live with their families, and that the states should also strengthen child protection systems (2, 23).

If it is impossible to provide adequate care for the child within the immediate family, the state should make all efforts to provide alternative care within the extended family or, if that is not possible, within the community in a family environment (23).

Similarly, contracting states are obliged to permit adoption system and to ensure that the best interests of the child should be paramount in the adoption process, while inter-state adoption may be initiated if the child cannot be accommodated in another family or be adopted, and the child cannot be adequately cared for in his/her country of origin (23, 67).

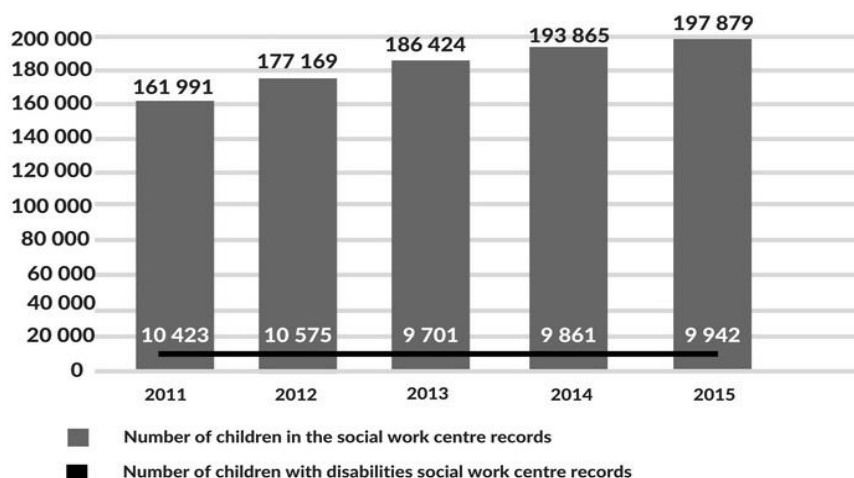
The text below will first present data on the work of social welfare centres as the basic institutions of social protection responsible for informing children and families, identifying children and families in need of support, and assessing, planning and coordinating the support itself.

This will be followed by analysis of the availability of social protection services in the community to offer basic support to children with disabilities and their families, as well as any other kind of support to the family. Finally, the alternative care system will be presented.

Centres for Social Work

In 2015 the records of centres for social work registered a total of 197,879 children (38). The average proportion of users of centres for social work in Serbia who are children is 28 per cent. The number of children with disabilities in the centres' records was 9,952, or 5 per cent of all registered children.

Figure 6: Children in the social protection system in 2015



The chart shows an increased number of children in the records but a slight decrease in the number of children with disabilities. By type of disability, in 2015 the centres for social work recorded that 35 per cent were children with physical disabilities, 21 per cent children with multiple disabilities, 20 per cent children with intellectual difficulties and 5.8 per cent children with pervasive developmental disorders (a group of neuropsychiatric developmental disorders characterized by delays and deviations in social and cognitive development, particularly in the areas of speech and language development) (38).

The network of centres for social work is well developed because every municipality has its own centre or a branch of a centre for social work (as some centres cover more than one municipality). In 2008 the Rulebook on the Organization, Norms and Standards of Work in Centres for Social Work (68) introduced the methodology of case management as a basic professional procedure for centres for social work. However, insufficient support to implement the reform led to professional practices (such as planning and assessment) being underdeveloped and difficulties with implementation. In addition, no work norms have been established and after the reform of centres for social work, professional workers spend 50 per cent more time on documentation than before the reform, while field work has almost completely ceased (69).

Since the centre is also a guardianship authority, most of its resources are used for legal protection, with advisory work with families in second place. This all therefore makes it difficult to recognize the needs of children with disabilities in timely fashion and to coordinate to provide services. It also leads to omissions in informing children and

families about their rights and opportunities for support. This is further proved by the findings of the focus groups organized for the Situation Analysis.

“No one offered me support or sent me anywhere. It was really hard. I had to do everything on my own, everything. No one even mentioned counseling. I went on my own and informed myself. I didn’t know anything. The association came much later.”

Mother of a child with disabilities

“First it is important to be informed – for us parents who don’t know our rights or our children’s rights. If we hadn’t been involved in the association and camps like this, we wouldn’t know what others were able to achieve and that we could achieve the same. It means that you have no source of information about where and what you could get. The state should start working on it.”

Mother of a child with disabilities

These data suggest that there are important barriers to informing parents about available support, though it is not just the responsibility of the social protection system but also of the healthcare system and civil society organizations.

Parents are most likely to mention civil society organizations as their main source of information, primarily informal parent groups. In all focus groups parents also mentioned problems becoming informed about available and necessary support for their children with disabilities. Parents often use the internet for this, but, given the multitude of contradictory and sometimes untruthful information it is more stressful than informative.

The focus groups also pointed to the lack of early counselling services, particularly in situations when parents learn that their children have developmental disorders and/or disabilities. Almost all these parents say that in such situations they are absolutely left on their own.

“I absolutely didn’t know where to go. Home? Your whole world is destroyed. And then you come home and you mustn’t cry, you can’t, you mustn’t say anything because grandma and dad and the others will start crying. And then you just keep looking at the child and you simply can’t believe it. You wonder whether all that is really possible »

Mother of a child with disabilities

Services in the local community and informal support

Total expenditure on social protection services by local self-governments in 2015 was 2.6 billion dinars (about 0.065 per cent of GDP).

This expenditure is half that for residential and family accommodation, amounting to 5.8 billion dinars (about 0.14 per cent of GDP).

Eighty-six per cent of service financing in 2015 came from local self-government budgets (70).

Social protection services in the community and informal support services play very important roles in upholding children's rights to life in the family, particularly in the de-institutionalization process and prevention of further institutionalization of children and adults with disabilities. They are crucial for providing life in the community, upholding of rights and social inclusion of children with disabilities.

In order to encourage the development of social protection services at local level, legislative amendments stipulate pluralism of service providers, and civil society organizations were given the chance to provide various social protection services in the community.

However, the mapping of social protection services shows that service provision is dominated by the state sector, which provides services for 74 per cent of users compared to 26 per cent provided by the non-state sector⁴⁰.

In 2015 social protection services were being provided in 133 out of 145 local self-government areas, with the most common being house help for the elderly and day care for children with disabilities. However, no services were provided in 12 self-government units. Furthermore, house help is only available for children in 14 per cent of the municipalities and day care in 47 per cent of municipalities. This shows that basic services for children with disabilities are not developed in most communities, and current service capacities do not meet the local community needs (70).

⁴⁰ Development of social protection services by civil society organizations is hindered by unstable financing as well as by demanding standards, primarily in relation to the documentation about space requirements.

The overview of social protection services shows that services for children with disabilities are insufficiently developed or widespread (Table 2) shows that the services for this category of children are insufficiently developed or widespread (70).

Table 2: Social protection services

Social protection service	Number of local self-government units offering the service		Share in the total number of local self-government units (%)	
	2012.	2015.	2012.	2015.
Home helps for children	37	20	26%	14%
Day care for children and young people with disabilities	71	68	49%	47%
Child's personal companion	/	30	/	21%
Respite accommodation	11	9	8%	6%
Supported lodging for persons with disabilities	5	13	3%	9%

The day care service for children and young people with disabilities is provided more regularly, mostly without large interruptions during the year, while several day care centres provides this service for more than eight hours a day. The number of local self-government units providing home help for children with disabilities has fallen by 46 per cent in the period from 2012 to 2015.

In many local self-government areas there are no services such as day care centres, home helps, respite care, therapeutic counselling, and personal companions, and they are not equally available throughout Serbia. In addition, there are not sufficient places for all children, the quality of services is not uniform, the staff are sometimes not well trained and financing by local self-governments is not sustainable (71).

In 2016⁴¹ the Republic of Serbia introduced dedicated transfers to local self-governments with the aim of developing social protection services. These funds were reserved exclusively for initiating and operating social protection services for the most vulnerable groups including, among others, children with disabilities. The dedicated transfers are specifically intended for social protection services for local self-government units with

⁴¹ Although dedicated transfers were introduced in the 2011 Law on Social Protection, their use did not begin until 2016.

development levels below the national average, or for local self-government units where residential institutions in the process of transformation are located, as well as for innovative services and social protection services of special importance nationally (72).

In 2016 the Government of the Republic of Serbia decided to allocate 400 million dinars from its budget for dedicated transfers. In 2017 the allocation was increased to 700 million dinars.

Family associate for families of children with disabilities

One of the important services in the social protection system for families of children with disabilities is that of the **family associate**, who is intended to prevent family separation and child institutionalization. They provide intensive, comprehensive and continued support to parents and families to ensure that children with disabilities can remain in the local community.

This service is particularly valuable because the family associate is engaged in inter-sector cooperation at local level, on the one hand working directly in the family home with parents, children and other important persons on the one hand, and on the other hand, connecting the family with the education system, healthcare institutions and social protection services, local self-government bodies, public services, citizen associations and other organizations and institutions in the local community.

The service is intended to be offered once a week over a one-year period and includes psychological support and counselling, support for health protection (information and counselling), learning support and cooperation with education institutions, psychosocial support (building a social network of the family and child, inclusion in various activities in the local community, connecting with other services etc.).

During the piloting process (between May 2015 and April 2017) support was provided to 189 families with a total of 228 children with disabilities (61.5 per cent boys), while eight family associates were engaged to work with families living in multiple deprivation with very complex needs, where there were frequently additional risk factors, such as diseases and disabilities in parents, low socio-economic status, single-parent families, parents with low competences, or lack of family and social support, as well as childhood disability.

About 20 per cent of the participating families are Roma: this is substantially higher than the proportion of Serbia's population who are Roma (2 per cent). As many as 56.8 per cent of surveyed children had intellectual disorders, followed by children with specific developmental disorders (including ADHD and behavioural disorders).

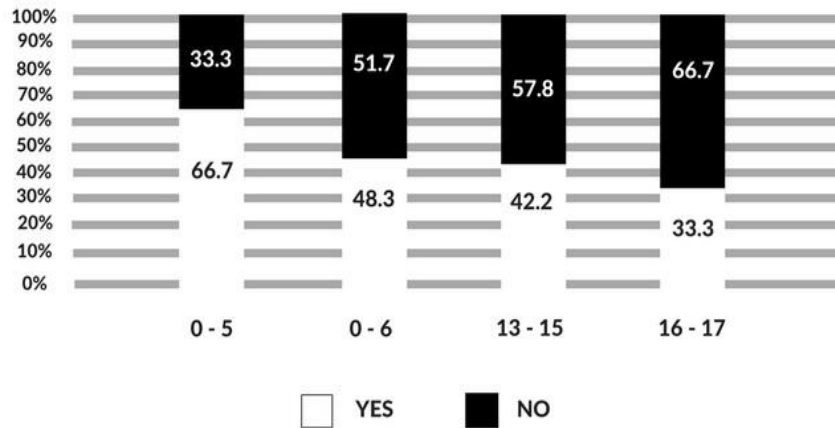
Most of the children were in the education system. The plurality of parents' educational attainment level was completing secondary school (41.7 per cent of fathers and 35.9 per cent of mothers), but as many as 6.8 per cent of fathers and 14.6 per cent mothers had not completed school, and thus categorized as illiterate.

The service piloting and evaluation confirm that the service serves its purpose, strengthens families and prevents separation of children from the family environment. Progress was achieved in over 80 per cent of the families involved, while seven children from four families were moved (1.6 per cent of all the children using the service). The pilot found that the groups requiring most support were single-parent families, families with two or more children with disabilities and families with children suffering from chronic diseases excepting developmental disorders. In almost half the families using the services the source of income was social benefits, while single-parent families and Roma families lived in the worst conditions and worst material deprivation. The pilot revealed the importance of coordination and multi-sector cooperation (social protection, health care, education) and of connecting different actors. The evaluation emphasized that "this service shows high efficiency in preventing the displacement of children with disabilities from the family, as well as in family reunification, while it also shows potential in support to early stimulation programmes for children (73).

Low availability of services for children with disabilities in the community is confirmed by the survey of parents for this Situation Analysis. The survey revealed that day care centres are only available to less than a fifth of the children (19.1 per cent), and respite care for only 1.6 per cent.

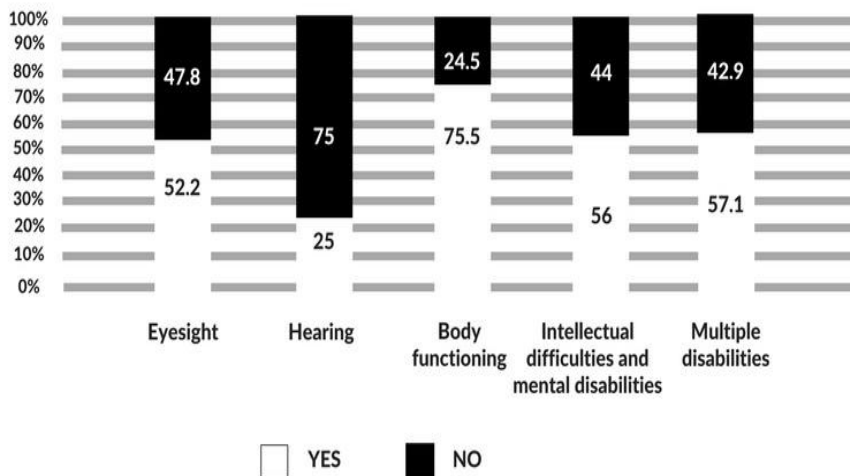
Families rely much more on extended families than social services for support: 44 per cent of the families use this resource. A further 16 per cent of families rely on support from their neighbours for raising the children. The most support of all kinds is provided to the parents of younger children, but the support gradually decreases as the children get older, though support requirements increase: this further highlights emphasizes the lack of services.

Figure 7. Is any member of your extended family currently helping you to raise your child with disabilities? (by age group)



Fifty-nine per cent of the families state that raising the child with disabilities has substantially worsened family functioning. Most such difficulties were encountered by the families of children with physical disabilities, then with intellectual difficulties, mental disabilities and multiple disabilities.

Figure 8. Has bringing up the child with disabilities generally worsened your functioning as a family or not? (shown by dominant disorder)



The survey for the Situation Analysis revealed that mothers are usually the primary carer for children with disabilities (56.3 per cent), followed by both parents together (31.7 per cent). In 5.5 per cent of cases the father is the primary carer, and in 6.6 per cent other persons care for the child.

The survey results show that the additional care needs of their children mean that almost half of the parents (40 per cent) are prevented from participating in community activities

Special childcare leave

In order to support families of children with disabilities and ensure care for the children, in addition to social protection services, national legislation also stipulates special childcare leave from work related to the need for continued care and assistance for children with disabilities in the first years of their lives.

Compulsory health insurance regulates income compensation during childcare leave, and the leave of absence for the insured person to care for a child with disabilities is determined according to the child's age and the severity of the disability (74).

This kind of support may be used by one of the parents (guardians, foster parents or adoptive parents) of the child, after the end of maternity leave and absence from work for childcare. The individual has the right to be absent from work or to work half-time until the child is at most five years old.

Although parents are entitled to leave from work to care for the child until the child is five years old, female participants at the Situation Analysis focus groups often claimed that they were unable to exercise this right.

"I didn't get sick leave from the specialist doctor. Though leave can last up to five years I had to return to work when my child was three."

Mother of a child with disabilities

Alternative care

In the past decade Serbia has achieved outstanding progress in de-institutionalization, and the rate of child institutionalization is among the lowest in Europe. Apart from the development of family accommodation (foster care), one of the causes of the small number of children in residential care is the low rate of child separation, which stands at eight in 10,000 children (75). Since 2010 the number of children in residential care institutions for children and young people has fallen from 1,265 to 716^{42,43} (a 43 per cent reduction), while the number of children in foster families has increased from 4,586 to

⁴² Children living in institutions for children and youth excluding the institute for education of children and youth

⁴³ At the end of 2016 there were 1,992 residents of institutions for children and youth, of whom 716 were children (36 per cent), while children and youth also shared accommodation with adults. Of all those in residential care in the whole of 2016, children made up 38 per cent of residents of institutions for children and youth, while 25 per cent were aged 18-25 and as many as 38 per cent older users (including elderly persons). This shows the problem of accommodating adults and children in the same institutions.

5,320 (76, 77). Children in large institutions are still accommodated with adults, leading to substantial risks to their wellbeing. The total number of children in the non-family care system⁴⁴ at the end of 2016 was 6,036, 22 per cent of whom were children with disabilities (four times more than the assumed 5 per cent in the general population).

Children with disabilities are particularly predominant in residential accommodation, making up 80 per cent of all children in such accommodation today (77).

Small residential homes, a more appropriate form of accommodation, took in only 3 per cent of those living in residential care facilities for children and youth (77), and larger-capacity facilities predominate. This indicates that the de-institutionalization process does not adequately address the needs of children with disabilities or their families.

In addition to most children in institutional accommodation having disabilities, institutionalization of very young children is also a concern. This occurs despite the legal prohibition on accommodating children under three years of age without the approval of the ministry responsible for social protection.

At the end of 2016 a total of 31 children under three years of age were in institutional care, in the Centre for Protection of Infants, Children and Youth in Belgrade and “Kolevka” Home in Subotica (76). While the number of young children is decreasing every year, children still come to the institutions directly from the healthcare system. In 2016, 16 per cent children in the homes came directly from the healthcare system because of their difficult medical conditions (Table 3), an increase of 4 percentage points from 2015, though at the same time there was a fall in the number of children entering residential institutions that were primarily for children with disabilities, from 12 per cent to 1 per cent^{45 46} (55, 77).

⁴⁴ Accommodation in social care institutions and family accommodation (foster families).

⁴⁵ The most common medical conditions listed as reasons for institutionalization of newborn babies with disabilities are chromosome aberrations (37 per cent), pathological states appearing in the neonatal period (33 per cent) and inborn morphological disorders (22 per cent).

⁴⁶ Categorization of institutions for children and youth with disabilities, or institutions for children and youth accommodating primarily children with disabilities, is not based on legislation, but on the manner of reporting of the Republican Institute for Social Protection. Detailed reporting is required for all institutions for children and youth, without dividing them into institutions for children and youth with disabilities and those for children and youth.

A parent at a focus group had this to say about the practice of sending children immediately after their birth to social protection institutions:

"She said that she warmly recommended the institution, and told me exactly which one. When we asked her if she had ever been there, she said no. How can you warmly recommend something you have never seen? Then I took a bus to see the institution. After that I didn't know what to do for six months. I had a constant headache. Then I said that I would fight for my child."

Mother of a child with disabilities

Experts have established that, medically speaking, institutionalization is only justified in a small number of very rare cases (78).

According to official data, insufficient support for parents to care for the medical needs of their children with disabilities is still the most common reason why children are placed in institutions for children and youth which are designated primarily for children with disabilities (77 per cent) (77).

In this context, the Committee on the Rights of the Child has recommended that Serbia should "Immediately reduce the placement of children under the age of 3 years, including those with disabilities, in residential care institutions and expedite placement in family-based care; and ensure adequate safeguards and clear criteria, particularly for Roma children and children with disabilities and on the basis of the needs and best interests of the child, for determining whether a child should be placed in alternative care" (11).

The Committee on the Rights of the Child and the Committee on the Rights of Persons with Disabilities have also expressed concern about the overrepresentation of children with disabilities in residential accommodation, as well as about inadequate living conditions in large residential institutions, and the fact that children are exposed to segregation, neglect, limited privacy, exclusion from education and games, and sometimes potentially inadequate medical treatment without informed consent.

Table 3: Basic indicators of the status of children in homes for children and youth in 2016

	Homes for children and youth (11 institutions)	Homes for children and youth with disabilities (5 institutions) ⁴⁷
Children (from 0 to 17)	445	281
Youth (from 18 to 25)	156	354
Older (25+)	1	794
Environment from which children come into accommodation		
Biological family	31%	39%
Family accommodation	17%	17%
From a medical institution	16%	24%
From other institutions	19%	15%
Other	16%	5%
Reason for accommodation		
Inadequate parental care	33%	4%
Parents' inability to respond to the child's medical problems	20%	77%
Parents being prevented from carrying out parental duties	10%	4%
Deprivation of parental rights	18%	15%
Violence to the child	5%	/
Deceased parents	5%	/
Parents' deprivation of ability to work	3%	1%
Other reasons	6%	/
Length of the stay in the institution		
Up to one year	18%	2%
1–2 years	17%	4%
3–5 years	29%	9%
6–10 years	20%	12%

⁴⁷ These data are not disaggregated in the report for children only but refer to all users (children, youth and adults).

11 years or more	16%	73%
Disabilities		
Percentage of children and youth in accommodation with disabilities	60%	100%
Education		
Included in education	88%	57%
Reasons for leaving the accommodation		
Becoming independent	32%	/
Conditions created for return to the family (biological, kinship)	18%	20%
Transfer to a foster family	6%	20%
Transfer to another institution	24%	10%
Adoption	5%	/
Death	4%	50%
Other	11%	/

Accommodation conditions are often poor and insufficiently stimulating, with a large number of users in each rooms and children with disabilities being excluded from the education system, while lacking sufficient rehabilitation and treatment. Some institutions recorded excessive use of medicines, restraint measures and isolation (79).

The children who need the most intensive support are in the worst position, in special wards where they spend days lying in bed, with minimum interaction with others and without rehabilitation or support programmes. The data show that although the centres record a plurality of children with physical disabilities, the institutions most frequently accommodate children with intellectual and mental disabilities, and children with multiple disabilities, additionally proving the higher institutionalization rate for this group of children (38, 77). Although as many as 95 per cent of all users of homes for children and youth with disabilities have parents (77), a very small number of them regularly contact or spend weekends with their immediate or extended families.

The fact that many families of children with disabilities live in poor socio-economic positions and that the residential institutions are far from the parents' places of residence reduces the opportunity for regular meeting and accordingly affects regular contact and potential conditions for the child to return to the family.

Therefore, the CRPD Committee has recommended that Serbia should reform the social support system for children with disabilities and their families in order to improve

connection and coordination and avoid unnecessary institutionalization, and also carry out public campaigns to combat stigmatization and prejudice about children with disabilities (11).

As many as 87 per cent of Serbian citizens think that children with physical or sensory difficulties should live in families instead of specialized institutions, while 79 per cent think the same about children with intellectual difficulties (27).

According to available data, in 2015 there were 762 children with developmental and medical problems in alternative family care, making up 14.3 per cent of all children in alternative family care (38). This equates to a little more than half of the children with disabilities in state care (56 per cent) living with alternative families. It should be noted that a certain number of children and youth are transferred from family accommodation to homes, indicating need for further analysis of this trend in order to find other ways to strengthen this form of care.

The Committee on the Rights of the Child has recommended that Serbia should establish legislative and other measures to ensure that children with disabilities who need constant care stay with their biological families through child and family services and/or financial help and support to parents who are unable to work and earn livings because they have to care for the child.

The parents who participated in the focus groups for the Situation Analysis expressed negative opinions about family care (fostering).

“I think that if you have to give your child to a foster family, the state should allow you to be the foster parent because that foster parent will not take care of your child like a real parent. I think that the only place where it isn’t regulated is our country and that is a real shame.”

Mother of a child with disabilities

“They have all the privileges while we as parents have nothing.”

Mother of a child with disabilities

“Tell me, please, why I should give my child to a foster family? I don’t understand their way of thinking. They get an income and all other benefits from the state while you as a parent don’t get anything. Plus you are condemned to give your children away! And what if you can’t work... What if you quit working in the company... If you have to spend 24 hours a day with the child, this social worker will come and tell you that your child is living in

inadequate conditions and then your child will be taken away. I don't understand that way of thinking!"

Father of a child with disabilities

The main reason for the negative attitude to fostering is the participants' perception that foster families receive plenty of support, primarily monetary, which is not available to parents though they have difficulty meeting their children's basic needs. Despite the fact that substantial funds are put aside for the alternative care system, in Serbia there have been no studies yet investigating the outcomes of using these services.

Adoption

In the course of 2016 there were 128 adoptions, which is 18 per cent lower than 2015 and as much as 34 per cent lower than 2014. According to the records of the centres for social work, on 31 December 2016 a total of 217 children were eligible for adoption, which means that the adoption rate is about 60 per cent, although there were 418 adoptive families available. The analysis of the documentation of the children in care indicates that the centres for social work do not initiate adoption processes even when it has been established that the family can no longer take care of the child, leading to the prolonged stay of the children in state care (80). Children with disabilities are usually adopted through international adoption, which makes up 9 per cent of all adopted children.

Health Protection

The healthcare system is one of the systems with a crucial impact on the welfare of children with disabilities, both because it is the first system able to offer support to the child and the family and because of the importance of healthcare for children with disabilities and their families. Legislation and strategic frameworks in the Republic of Serbia guarantee universal availability of healthcare services to all children, including children with disabilities. Currently a network of development consulting services is being developed and improved to offer individualized and adjusted support to children with disabilities at primary healthcare facilities. Almost two thirds (62 per cent) of parents think that healthcare services are of high or very high quality, while 32 per cent think that they are of low quality and 6 per cent think they are of very low quality.

Parents primarily see challenges in the area of recognizing disabilities, i.e. early intervention and diagnosis, or in the availability and quality of early intervention. Although efforts made in recent years to improve the quality of paediatric and patronage services will meet the needs of the families in early childhood, particularly concerning children with disabilities, these needs have not been met yet. Namely, development consulting services in which the key role is played by paediatricians still lack adequate resources, and are not evenly distributed, making access to and quality of services uneven. Moreover, there are problems at all levels of healthcare caused by the frequently lengthy process to provide adequate diagnosis and adequate healthcare, as well as insufficient sensitivity or knowledge among medical staff to work with children with disabilities. In addition, healthcare professionals rarely refer parents to non-healthcare support systems even when such resources exist in the community, and the practice still prevails of sending children with disabilities into residential care.

However, looking at the availability of services for children with disabilities and their families, healthcare services are the most accessible (87 per cent of parents stated they were accessible to them) so they currently constitute the basis of the Government's response to the needs of children with disabilities and their families at birth.

When using healthcare services parents also encounter uneven availability of services, particularly for therapeutic treatments for which there are long waiting lists. In a survey conducted for the Situation Analysis, 48 per cent of interviewed parents said that their children with disabilities had partially constrained access to healthcare services, 14.8 per cent said it was constrained to a large extent, and 37.2 per cent said that it was not constrained at all. In this context, and given parents' desire to help their children and

insufficient information about adequate forms of healthcare for children with disabilities, parents sometimes decide to turn to private healthcare service providers which are outside the healthcare system and perform unapproved forms of treatment, which can lead to substantial risks to the health of the child. Therefore the Ministry of Health has begun producing a guide to screening, diagnostics and treatment of children with certain disabilities. Currently it is impossible to estimate the number of children with disabilities using healthcare services because data is not kept in an accessible format. Substantial progress in record keeping is expected after the introduction of the Register of Children with Disabilities.

The healthcare system is crucial for the development and welfare of children with disabilities and their families, since it is the first system they are directed to from birth itself. Children with disabilities receive medical insurance based on their parents' insurance and if their parents are not insured, healthcare protection is paid for from the national budget.⁴⁸

According to the Law on Health Care (81) and the Law on Health Insurance (82), all citizens are entitled to access to healthcare without any discrimination, including prevention, early diagnosis, treatment and rehabilitation.

Many strategic documents have been adopted to improve public health and harmonize healthcare standards with the applicable EU standards. These include the National Programme of Healthcare for Women, Children and Youth, the National Programme for Early Childhood Development, and the National Programme of Preventive Health Protection for Children with Psycho-physiological and Speech Disorders.

The healthcare system currently has no clear estimate of the number of children with disabilities who are provided with healthcare services. Data from 2015 suggest that 37,000 children with disabilities aged up to seven used healthcare services that year. However, it is impossible to establish definitively whether this number of children is

⁴⁸ The right to health protection includes: measures for prevention and early detection of disease; examinations and treatment of women related to family planning and during pregnancy, childbirth and maternity up to 12 months after childbirth; examinations and treatment in the event of illness and injury; examinations and treatment of mouth and dental diseases; medical rehabilitation in the event of illness and injury; medicines and medical devices; prostheses, orthoses and other aids for movement, standing and sitting, sight, hearing and speech aids, dental compensations and other aids.

correct because data are usually calculated by the number of services provided rather than the number of users.

The number of services rendered cannot be taken as a good indicator of services rendered to children with disabilities, because in healthcare centres with established development consulting services, staff say they are unable to record services provided only to children with disabilities, and that they are recorded in different ways.⁴⁹ Therefore, healthcare system actors believe it is necessary to adopt a new classification of services. Records of children with disabilities and monitoring of the healthcare support necessary will be significantly improved by adoption of the Register of Children with Disabilities under the existing legislative framework (83, 84). Since the Register is based on the International Classification of Functioning, Disability and Health, children's version (ICF-CY), the assessment will be in line with the Convention on the Rights of Persons with Disabilities.

The number of employed health professionals for women and children (paediatricians, gynaecologists and medical staff) in health centres is decreasing in the Republic of Serbia. There is a deficit of 250 paediatricians in outpatient health centres when set against the applicable norms and standards. It is essential to replace the personnel immediately because otherwise in five years the deficit will rise to 380 and in ten years to 659 paediatricians

In the past decade significant efforts have been made to improve this area so the healthcare system can better respond to the needs of children with disabilities more adequately and be involved during the child's early life.

For children with developmental difficulties and disabilities, early recognition and early interventions are crucial for their successful development. Paediatricians play the most important role in recognizing obstacles to the development of children with disabilities.

Under national programmes, all children have access to specialized screenings in the maternity ward (such as for hearing, hypothyroidism, phenylketonuria) and adequate therapy.

⁴⁹ Paediatrician services in development consulting centres are billed for 230 dinars (US\$2.40) and recorded as a control medical examination.

Subsequently children undergo **preventive medical examinations** which are, depending on the age, routinely performed for newborns, infants and toddlers⁵⁰ and mostly involve becoming familiar with children and their families, assessing development and identifying potential deviations, assessing extant protection and risk factors to the health of the children and their families, physical examinations, individual healthcare instruction, assessing vaccine status and acting by the applicable vaccination calendar, referring children for necessary laboratory tests and other screenings, referral (if necessary) to the development consulting centre or other specialist doctors for consultations and examinations. Recently new instruments have been introduced to screen and monitor child development in paediatricians' everyday practice (child's age and development stages, a guide for monitoring child development, the M-CHAT test for autism-related disorders and so on) and this has increased the accuracy of identifying children who need additional developmental support.

Preventive control examinations are planned on an annual basis but may be performed more frequently for newborns and toddlers if certain developmental problems have been recognized. Apart being examined by a paediatrician, children should also be examined by a speech therapist; an ophthalmologist; a dentist; an ear nose and throat specialist; and a physical medicine specialist.

The **visiting nurse service** is an important support programs for newborn children and families. The nurse should visit a pregnant woman once and a woman with a high-risk pregnancy several times, as well as visiting every newborn child and his/her mother five times, with two more visits during the child's first year, and one visit each in the second and fourth years. If any difficulties or disabilities are observed in the child and his/her family, the health visitor should visit them twice more in the first year or more frequently if requested by the paediatrician if it has been established that the family requires additional support. Nevertheless, visiting nurses paid the smallest number of visits to families with children with disabilities amounting to only 0.2 per cent of the total number of visits to the general population (86).

The role of the visiting nurse is important because he/she spends time with the newborn child in the family environment, becomes familiar with the health of the child and the mother, as well as of other members of the family and gains insight into their general living conditions.

The visiting nurse assesses the presence of various risk and protection factors, assesses the parents' knowledge and behaviour regarding care and nutrition for the child, informs

⁵⁰ Performed when the child is 1, 2, 3–5, 5, 6, 9, 13–15, and 18–24 months old and 4 years old.

and educates the parents about child care and stimulation as well as the importance of eliminating negative parental practices, and provides information and support with contacting other services or systems in the community.

Visiting nurses are of particular importance to families of children with any disabilities or developmental difficulties, for poor Roma families and for all other vulnerable population groups.

Problems in the healthcare system, particularly for children with mental and/or multiple disabilities, also result from inadequate and frequently-delayed diagnosis, meaning that families and children lose valuable time that should be used for initial treatment, rehabilitation and other measures and interventions. Although most parents (59.5 per cent) recognize that the child has a disability either at birth or during the child's first year, the process of establishing a diagnosis and adequate treatment is usually protracted.

“Then it started – she would start walking and then fall, not being able to get up, staggering. Then you couldn’t imagine what had happened to the child who was running around the day before. She was able to walk upstairs and downstairs. She could do all those things and now suddenly she couldn’t get up. Then I started giving her a hard time, simply because the doctor told me that she wanted more attention. So I kept telling her to get up and do this or that. Then I saw that she was really trying her hardest and using all her strength, not wanting to cry. Still I could see tears in her eyes because I didn’t believe her. And once again I took her to the paediatrician who repeated that there was nothing wrong with her. ‘Everything is fine, she can walk like a model’. So I was made out to be paranoid. For a period you don’t do anything but it is not normal to sit down and wait when you feel something is wrong. Then I had to find some people to help me and send me to the doctor in the cerebral palsy clinic in Sokobanjska...”

Mother of a child with disabilities

“We also went from one doctor to another. We basically lost three or four years because the paediatrician kept saying that she was spoiled and would start talking one day. Like she takes after her father and he started talking late. That’s nonsense.”

Mother of a child with disabilities

By the age of three 83.6 per cent of parents realized that their children had disabilities. An important problem emphasized by the parents in focus groups for the Situation Analysis is that doctors do not give information to parents adequately.

“Well, you know what, when I got the first report from Belgrade, I didn’t know anything about the diagnosis. I went first to our doctors here in Zrenjanin and they felt pity for my child and said that unfortunately she had to go to a special school.”

Mother of a child with disabilities

“They just told me about the diagnosis but they didn’t send me anywhere to get support.”

Father of a child with disabilities

“From that test result they could see that the child had muscular dystrophy. They hid the test results from me for about five days. They didn’t want to tell me. After five days I went in and asked for the results because I knew they had them but wouldn’t tell me the truth. And then the doctor told me straight out that my child would die in a month and that we should leave him.”

Mother of a child with disabilities

“I am thankful to doctors for being able to recognize such a serious and progressive disease within a week. I don’t know whether it was pure luck or that the doctor knew. She sent me immediately to the Muscular Dystrophy Association.”

Mother of a child with disabilities

“After the diagnosis, we went for a control check-up. I told them what my child could do and the doctor replied: ‘Well, mum, you are torturing the child’. Then he told me that I should take him to a residential institution. I just didn’t know how to leave him and how the doctor could think that way. Afterwards I never went for a check up. I don’t need such an opinion.”

Mother of a child with disabilities

Even when certain disabilities have been recognized, there are no early intervention services that are individualized, family-focused, holistic and directed at increasing the child’s capabilities.

Healthcare system representatives have observed that healthcare professionals are not capable of working with children with disabilities. They consider it necessary to introduce topics of early development and support to children with disabilities in the initial training of healthcare professionals, in both their basic studies and their specialization.

Developmental counselling units have been recognized as one of the main mechanisms to improve medical treatment for children with disabilities, particularly with regard to early intervention. Developmental counselling units are the most common functional units within paediatric services and involve interlinked activity by healthcare professionals and associated personnel (paediatricians, senior nurses, defectologists, psychologists, social workers and pedagogues working half-time). They should coordinate well and provide the support most children with disabilities require.

There are 35 developmental counselling units in Serbia, but not all of them are fully functional. Most counselling units lack both equipment and premises designed specifically for their work, and only 12 of them have been assessed as equipped to ensure a pleasant atmosphere for children. Only three counselling units (in Zrenjanin, Sremska Mitrovica and Zemun) have paediatricians working full-time the service. Apart from establishing separate organizational units and furnishing all the counselling units, it is also necessary to employ paediatricians specially educated to work with children with disabilities at the services. In practice, the paediatrician selected is usually one who works in a pre-school service and then spends part of his/her working hours in the developmental counselling unit. This is not enough for adequate and full support to children, particularly when it comes to working with parents.

Both paediatricians and health workers should also receive additional education about child development and modern concepts and approaches in the area of early intervention. In addition, education about modern approaches to early intervention should also be included in the curriculum for elementary schooling.⁵¹

Youth counselling centres that are intended to provide psychological support and improve reproductive health face similar challenges to developmental counselling units for children, including the insufficient number of such centres in some areas of the

⁵¹ Currently guidelines for screening, diagnosis and interventions are being made for children with autism-related disabilities, but generally there is not sufficient material addressing different speech disorders and disabilities.

country. One of the important roles of youth counselling centres is to advise young people about healthy lifestyles and sexual and reproductive health.

Because of factors such as social isolation, exclusion from regular schools, negative assumptions about their own sexuality and communication barriers (or unavailability of information in sign language, Braille, on audio tape or in other accessible formats), children with disabilities cannot obtain adequate education and information about sexuality: this is of particular importance for girls who are much more exposed to sexual violence. There were no available data for the Situation Analysis about how children with disabilities actually used youth consulting centres.

In interviews for the Situation Analysis healthcare system actors concluded that parents of children with disabilities are not sufficiently included in planning healthcare support for children. They believe that one of the deficiencies of development consulting services is insufficient work with parents, but also that there need to be paediatricians employed purely in the consulting services to ensure they have more time to work with users. This would improve service quality and the data collected by paediatricians about children. In order to achieve this, norms in paediatrics would need to be changed, because additional services cannot be developed with the same number of employees.

Apart from identification and early intervention, which are specific for certain disabilities, there are also problems during treatment of diseases that are not direct consequences of disability, such as dental, cardiological, neurological and oncological examinations. The basic problems identified are insufficient sensitivity among healthcare professionals or their lack of awareness about working with children with disabilities. This is demonstrated by the existence of stereotypes about children with disabilities, and from insufficiently developed skills to ensure adequate communication and participation in treatment (71). This often results in routine interventions, such as tooth fillings, being performed under general anaesthesia. Nevertheless, when assessing the quality of healthcare services, parents of children with disabilities generally find the service quality to be very high or high (62 per cent), while 31,7 per cent find the service quality poor, and 6 per cent very poor level (32). Although there is legal equality in the approach and quality of healthcare services for each child, and healthcare services are universally available to all children, parents think that access to health protection is rather difficult for a large number of children.

Legally, children with disabilities have the right to the full range of health protection within the compulsory health insurance. However, because of unequal access and insufficient service capacity as well as unreasonably long waiting lists for certain treatments, which leads to a substantial loss of time in the child's exercise of the right to a service or treatment in a healthcare institution, parents often pay for these services in private clinics (usually for speech therapy and psychological or physical therapies) (71). The existence of alternative service providers outside the healthcare system who perform unapproved forms of treatment without Ministry of Health permission is another important challenge for child healthcare.

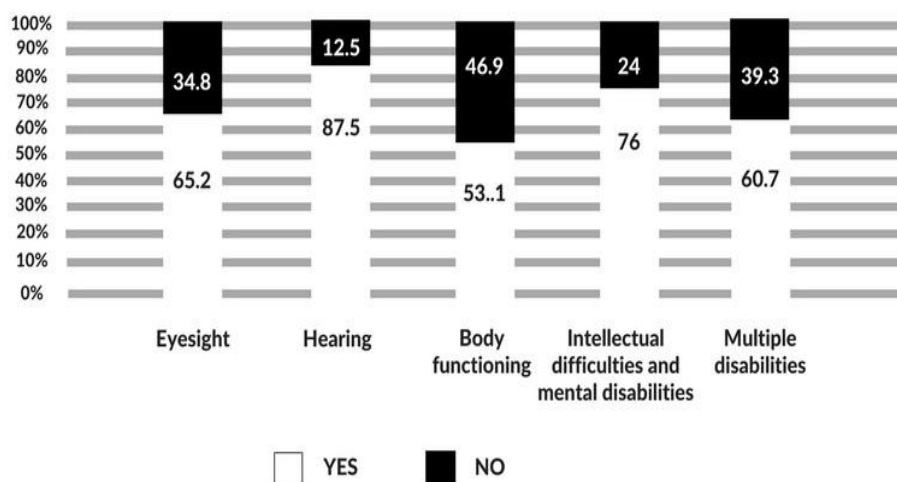
In their wish to ensure assistance to their children, parents also opt for such services because of the lack of information about medically approved treatments. Therefore the Ministry of Health has begun compiling guidelines for screening, diagnosis and interventions for children with certain disorders and disabilities (55).

In the survey conducted for the Situation Analysis, 48 per cent of interviewed parents say that their children with disabilities have some difficulty accessing healthcare services, 4,8 per cent find it very difficult while 37.2 per cent of them do not find it difficult at all (32). Similarly, 33.3 per cent of interviewed parents think that the local community does not provide all the healthcare services used by their children regularly, while most parents find that specialized healthcare services are either partially available (49.2 per cent) or completely unavailable (11.5 per cent).

Data regarding rehabilitation services for children with disabilities and the extent they are used could not be found for the Situation Analysis: more attention should be paid to this area in the future.

In the community where children live, health protection services are least accessible to children with physical and combined disabilities.

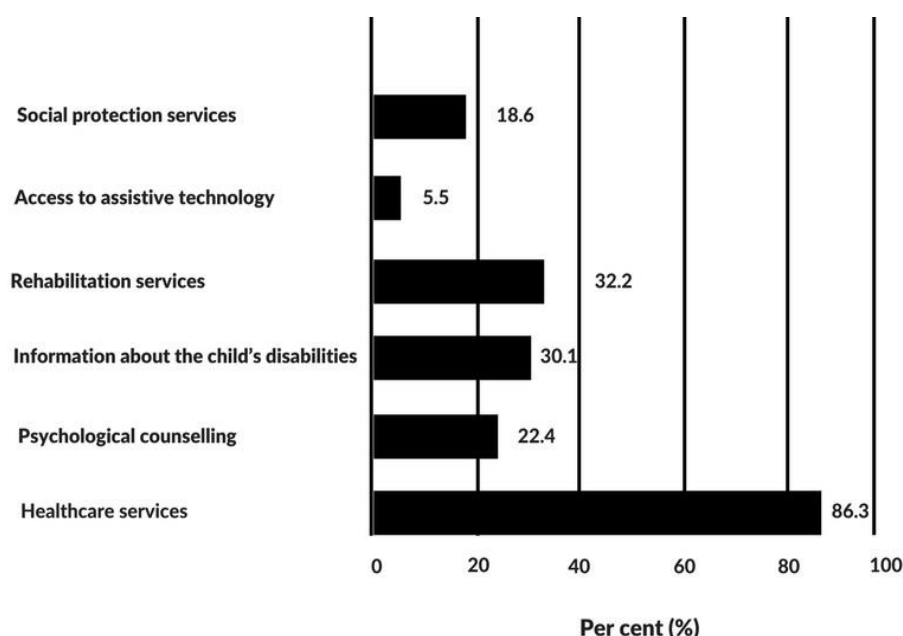
Figure 9. Are all the healthcare services regularly used by your child available in the community where you live? (Shown by the dominant disability)



In this context, the Committee on the Rights of the Child has expressed concern that access to early development centres/services, including referral to adequate medical and paediatric care, is still limited in Serbia, particularly for children with disabilities and children from socioeconomically deprived backgrounds. There are also substantial regional differences in access to development consulting services in the country.

However, when compared to other services to children with disabilities, or the level of use of various services, healthcare services are the most accessible services for children with disabilities and their families.

Figure 10. What support services were available to you at the time you realized that your child had a disability?



Parents in the focus groups also highlighted the lack of adjustment of healthcare procedures to children. For example, they referred to the continuous repeated examinations that are required to access healthcare rights even in cases where the child's health condition cannot be improved.

“They simply have no understanding of the things they should. For example, when it comes to medical aids, they ask for a new X-ray although the child's condition can never get better, only worse. So, if the X-ray was the same two years ago, why do they need another one...? And that is the way things go, but they don't approve spa treatment in the end.”

Father of a child with disabilities

“For example, when I take my child to the ophthalmologist, I have a problem. I spend half a day waiting there and then this older woman comes and tells the child: ‘Honey, come on, get up.’ Of course ‘I have muscular dystrophy’ isn’t written on the child’s forehead. I am tired of explaining to everyone that my child has weaker muscles and needs to sit and wait to be called in by the doctor. Sometimes they say that my child is not so small and can wait. That is sad, the fact that children have to wait just the same when they go to see a GP.”

Mother of a child with disabilities

As already stated in the social protection section, children are still sent directly from maternity wards to residential institutions for children with disabilities. Therefore, UNICEF and the partners have created and implemented a training programme, produced procedures and rules to inform parents about their children having disabilities, and innovated accompanying documentation. In order to reduce the institutionalization of newborn children, a series of measures has been defined, including the provision of timely information about the child’s health and continued family support. Specifically, the consulting team (the paediatrician-neonatologist and head nurse, and, if necessary, the directly responsible gynaecologist-obstetrician, social worker, psychologist and/or psychiatrist) will be available throughout the mother and child’s stay in the maternity ward and are obliged to refer the parents to all services which will subsequently be included in the optimal childcare (87). In December 2016 the Government also adopted new standards for the accreditation of maternity wards and neonatal care, which contain specific criteria and instructions for communication and support for parents whose children are born with disabilities.

Protection from violence and abuse

Children with disabilities are more vulnerable to abuse and neglect than children in the general population, particularly if they are housed in a residential institution. Although prevention and protection of children from violence should always consider specific disability-related risks and vulnerabilities, existing policies and programmes do not recognize them. Research shows that between 25 and 47 per cent of children have experienced violence, and they are four times more exposed to risks of becoming victims of physical violence by their peers and three times more exposed to risks of falling victim to sexual violence. Although almost all parents (60 per cent) took some steps to protect their children from violence, most frequently by reporting it to schools, in only a quarter of such cases did the person who committed violence against the child bear consequences. In most cases of violence parents think that the children do not need any rehabilitation support (64.4 per cent). However, even if they thought support was necessary, it was not provided in most cases.

The risk of abuse and neglect is particularly high for groups of vulnerable children such as children without parental care, children in institutions and children with disabilities (88). Children with disabilities are more vulnerable to various forms of abuse, whether in the family, at school or in private and public institutions, including residential institutions, while the risk of children with disabilities being abused is estimated to be five times higher than that of other children (3). The previous experience of abuse that is common among those children increases their risk of low self-respect, insecure attachment, developmental disorders and behavioural difficulties. The risk of abuse and neglect to children with disabilities is further increased by issues such as isolation and frequent rejection, communication difficulties, challenges raising and disciplining children, and lack of sex education (88). Although efforts to prevent and protect from violence should always be carried out in a way that considers specific disability-related risks and vulnerabilities, existing policies and programmes do not recognize this.

Despite recognizing children with disabilities as a group that is particularly vulnerable to violence, the Strategy for the Protection of Children from Violence, which expired in 2015, did not stipulate any special protection measures for these children.

Moreover, neither the General Protocol on Protection of Children from Abuse and Neglect (89) nor sector protocols provide or stipulate special measures for prevention, risk reduction and reaction for protection and rehabilitation procedures concerning children with disabilities.

Institutionally, responsibility for recognizing, reacting and eliminating violence and supporting children is divided among a large number of actors with specific roles and competences (social work centres, providers of social protection services, healthcare institutions, schools, police, prosecutor's offices and courts). Therefore, a successful response to violence against children with disabilities depends on the quality of work of each of these systems, as well as on the quality of cooperation between them.

Children with disabilities in residential institutions are additionally subject to risks of institutional violence and inhuman treatment. Therefore, the Committee on the Rights of the Child recommended that the Government in coordination with the Ombudsman's Office, in its capacity as the national preventive mechanism, should establish a monitoring mechanism to ensure that all children in institutions and alternative care are free from all forms of torture and inhumane or degrading treatment, and ensure that they have access to a confidential, safe and child-friendly mechanism for complaints related to their deprivation of liberty, their conditions of detention or internment and their treatment.⁵²

Moreover, the Committee on the Rights of the Child has pointed out that Serbia must ensure prevention mechanisms for the protection of children with intellectual and other psycho-social disabilities from all forms of physical and sexual violence and provide compulsory training on violence against children for all relevant professionals (11).

In general, we know very little about violence against children with disabilities. There are a few studies and publications on that topic, particularly on prevalence and risk factors regarding violence against children with disabilities, primarily violence against children in the family context.

The conclusions of these few studies show that children with disabilities are exposed to a higher risk of violence than children in the general population, and also at school or on the way to school.

⁵² This mechanism was established in 2011 and it visits residential institutions, including social protection institutions. However the extent to which this mechanism can change the situation in institutions without strong political support is unclear.

In joint research by the Association for Help to Mentally Challenged Persons (MNRO) and UNICEF in 2013, parents reported that 47 per cent of children with intellectual disabilities experienced a form of violence outside the family.

The results of the research also indicate that children with disabilities are four times more exposed to risks of physical violence from their peers and three times more exposed to risks of becoming victims of sexual abuse.

A 2014 study of school violence in Serbia (84), which was conducted in 237 elementary schools, also included seven special schools. Children from special schools are more likely to be involved in violent interaction than children in regular schools: this both reflects their exposure to physical violence (victims) and their violent behaviour to other children. While a third of the interviewed children from regular schools reported that children from other schools act violently towards them, as many as a half of the interviewed children from special schools say that they had had such experiences.

Children from special schools complained less about adult violence in comparison to children from regular schools (5.4 per cent compared 9.4 per cent for younger children, and 21.5 per cent to 33.6 per cent for older children).

On the other hand, attitudes of the staff in special schools do not differ substantially from attitudes of staff in regular schools. About two thirds of them think that the problem of violence is worse than before and that incidents of violence occur periodically. The situation is similar when it comes to attitudes about certain forms of violence: the concerns of special school staff are similar to those of staff in regular schools. It should be noted that some forms of violence are much more concerning to the staff in special schools: sexual harassment was reported to be a problem by 48 per cent of staff in special schools compared to 26 per cent in regular schools.

Similar findings were obtained in survey of parents for the Situation Analysis. A quarter of the parents (24.6 per cent) suspect that their children have been exposed to violence, while 14.8 per cent of children have been exposed to violence in the past year and 6 per cent to multiple incidents of violence (32). In cases when the parents suspected violence, 2.2 per cent of them informed the police, 13.3 per cent informed social work centres and 60 per cent informed school staff, while 20 per cent of the parents chose the "other" option. Of those parents who suspected violence against their children, 95.6 per cent took some action.

According to the parents, only a quarter of the persons committing violence against children with disabilities suffered consequences. In most cases of violence the parents think thought their children did not require rehabilitation support (64.4 per cent). Nevertheless, even in cases when they thought such support was necessary, it was not provided in most cases.

Conclusions and recommendations

The Situation Analysis reveals that currently there is no system to identify children with disabilities and their needs in line with the Convention on the Rights of Persons with Disabilities. This makes it more difficult to plan support measures, and assess the inclusion of children with disabilities and efficiency of the system in addressing their needs. Therefore, it is necessary to establish a coherent identification system to enable strategic planning and coordination to implement policies and measures to improve the position and exercise of the rights of children with disabilities.

The analysis of the legislative framework shows that the system for protecting children with disabilities is generally well-designed but that the key bottleneck is that there are no financial resources or mechanisms to sustainably finance its implementation. Therefore, support to children, although legally proscribed, is not available in practice, particularly in the education and social protection systems. In order to improve availability of support services for children with disabilities, better coordination of currently available resources and increased spending are needed: this also requires the design and implementation of a methodology to monitor investments in children with disabilities. It is also important to focus on increasing the accessibility of general institutions and services for children with disabilities rather than establishing specialized services and institutions designated only for children with disabilities.

The Situation Analysis shows that children with disabilities and their families are exposed to a range of forms of discrimination and in that context the following measures are of particular importance:

- To work to reduce prejudice and stereotypes against children with disabilities by conducting public campaigns and by educating employees in public administration and institutions
- To pay particular attention to the education system when protecting children from discrimination, because children are most frequently in contact with this system
- To try to increase the rate at which discrimination is reported to relevant bodies and to inform families and children with disabilities about measures for protection from discrimination

Parents of children with disabilities are much more exposed to the risk of poverty or having substantial financial difficulties in ensuring adequate support for their children. Therefore it is necessary:

- To introduce new measures or adjust existing ones to ensure protection of children with disabilities from poverty
- To introduce measures to support families of children with disabilities living in poverty by covering additional disability-related costs
- To change the method of assessment and amount of compensation for assistance and care of other persons to better suit the child's individual support needs
- With the aim of eliminating invisible poverty, to work to develop affirmative measures for the employment of parents of children with disabilities, and to harmonize their duties at work and at home
- To ensure access to social housing for families of children with disabilities and work to increase the social housing available

The analysis of education of children with disabilities indicates, first of all, a lack of support for children to participate in the education process as well as insufficiently-adjusted education practices. The lack of support in the regular education system for work with children with disabilities leads to divided opinions among parents regarding children's inclusion in the education system. Therefore comprehensive measures should be urgently taken to help children in regular education. It is necessary:

- To produce a national action plan for inclusive education
- To develop and finance additional support at both national and local levels for the inclusion of children with disabilities in schools
- To ensure efficient coordination among different systems concerning support needed for children with disabilities in the education process, and at the same time work to improve the position and work of inter-sector commissions
- To improve teacher competence to work with children with disabilities, primarily so they can better adjust teaching instruction to the needs of children with disabilities and improve their communication with children with disabilities
- To increase the accessibility of inclusive education for children with disabilities who live in residential institutions
- To strengthen connections between the labour market and the education of children with disabilities and enable them to develop skills and knowledge relevant for their subsequent participation in the labour market

Children with disabilities are not equally able to exercise the right to live in the community, that is in the family. Community social protection services, the prerequisite for the participation of children with disabilities in their communities, are still not sustainable or sufficiently developed. Therefore it is now necessary:

- To revise the method of financing existing community services to ensure their sustainability
- To use dedicated national-level transfers consistently to availability of support services to match the needs of children with disabilities and their families
- To work intensively to further develop community services for children with disabilities and their families, including improving the quality of these services
- To create conditions for adequate and timely recognition of the support needed by children with disabilities and their families
- To improve coordination and inclusion of community services for children with disabilities and their families, particularly services providing intensive support to families
- To develop the practice of informing children with disabilities and their families about their rights to social protection and about children's rights in general;
- To continue more decisively work to transform institutions in order to direct existing resources towards supporting families with children with disabilities, with the aim of preventing segregation and providing greater support for the child's return to the family, in line with the child's best interests

The healthcare system is crucial for early identification of disabilities and organizing early intervention services. Although it is more accessible to children with disabilities than other systems, the quality of healthcare requires improving, primarily through:

- Strongly supporting the development of early intervention services, particularly at development consulting centres, while introducing modern work protocols
- Generally improving the competences of professionals at all levels for early identification of disabilities, for informing families of children with disabilities and for providing initial support with learning and accepting that their children have disabilities
- Increasing the sensitivity of healthcare workers for work with children with disabilities and training them about the social model to disability and children's rights
- Increasing the adaptation of healthcare services to children with disabilities;
- Providing larger budget funds for more comprehensive coverage of the costs of healthcare and care for children with disabilities

Children with disabilities are exposed to an increased risk of violence and neglect in the family, at school and in the community, particularly when they are living in residential institutions. Therefore it is necessary:

- To work on prevent violence and protect children with disabilities from violence
- To bring perpetrators of violence against children with disabilities to justice, regardless of where the violence takes place or who the perpetrators are
- To adapt support measures and programmes for children who are victims of violence at all levels in order to make them an integral part of general policies and programmes in this area and taking into account the increased risks and vulnerability of children with disabilities

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