

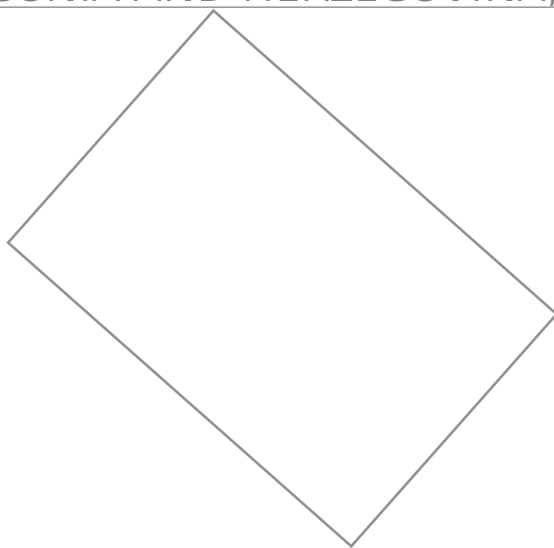


PRACTICING UNIVERSALITY OF RIGHTS:

ANALYSIS OF THE IMPLEMENTATION
OF THE UN CONVENTION ON THE RIGHTS
OF PERSONS WITH DISABILITIES IN VIEW
OF PERSONS WITH INTELLECTUAL DISABILITIES
IN BOSNIA AND HERZEGOVINA, KOSOVO, SERBIA

PRACTICING UNIVERSALITY OF RIGHTS:

ANALYSIS OF THE IMPLEMENTATION
OF THE UN CONVENTION ON THE RIGHTS
OF PERSONS WITH DISABILITIES IN VIEW
OF PERSONS WITH INTELLECTUAL DISABILITIES
IN BOSNIA AND HERZEGOVINA, KOSOVO, SERBIA



PRACTICING UNIVERSALITY OF RIGHTS: analysis of the implementation of the UN Convention on the Rights of Persons with Disabilities in view of persons with intellectual disabilities in Bosnia and Herzegovina, Kosovo, Serbia

This publication has been produced with the financial assistance of the European Union within the framework of the project „Balkan Regional Network for Social Inclusion“ implemented by: Kosovo Mental Disability Rights Initiative (K-MDRI), Mental Disability Rights Initiative – Serbia (MDRI-S), People in Need (PIN) and Union of Organizations for Support to Persons with Intellectual Disability of Federation of Bosnia and Herzegovina SUMERO. The contents of this document are the sole responsibility of People in Need, MDRI-S, SUMERO and K-MDRI and can under no circumstances be regarded as reflecting the position of the European Union.

The project is co-financed by the Czech Development Agency and the Ministry Foreign Affairs of the Czech Republic within the framework of the Czech Development Cooperation program

Authors:

The Convention on the Rights of Persons with Disabilities: Lea Šimoković

Bosna and Herzegovina: Sabina Čano, Halugić Dino, Nadarević Nermin

Kosovo: Vigan Behluli, Zamira Hyseni-Duraku

Serbia: Snežana Lazarević, Dragana Ćirić Milovanović, Lea Šimoković

Graphic design: EKD Studio

Number of copies: 500 pcs

Contents

Forward	11
Executive Summary	23
Introduction	26
<u>The Convention on the Rights of Persons with Disabilities</u>	28
Article 12 - Equal Recognition Before the Law	29
Importance and Development	29
Authoritative Opinions	30
Legal Context of Decision-making	31
Deconstructing the Obligations	32
Conclusion	33
Article 19 Living Independently and Being Included in the Community	33
Deconstructing Obligations	34
Timing of Obligations	35
Conclusion	36
Article 24 Education	36
Importance and Development	37
Core Dilemma	37
Deconstructing Obligations	38
Authoritative Opinion	38
Conclusion	39
Article 27 Work and Employment	39
Value and Importance	40
Deconstructing Obligations	40
Authoritative Opinion	41
Conclusion	42
<u>Bosnia and Herzegovina</u>	35
The B&H Constitution	35
Strategies and National Disability Plans	35
Equal Recognition before the Law	37
Legal and Policy Analysis	37
Procedures for Deprivation of Legal Capacity	37
Analysis of Practice	39
Conclusion	43
Living Independently and Being Included in the Community	46
Legal and Policy Analysis	46
Legal Framework	46
Analysis of Practice	48
Analysis of the Quality of Services in Social Protection Institutions in FB&H	50
Right to Privacy of Residents in Institutions	52

Health Care Service in Institutions	54
Education in Institutions	54
Community Based Services	57
Personal Assistance Service in the Community	58
Institutions vs. Services in the Community	60
Successful Deinstitutionalization	64
Conclusion	64
Education	67
Legal and Policy Analysis	67
Legal Framework	67
Latest Change of Laws	67
School Enrolment	68
International Documents and National Strategies for Education	68
Analysis of Practice	69
Enrolment in Education	69
Conclusion	73
Work and Employment	75
Legal and Policy Analysis	75
Legal Framework	75
Conditions for Employment of Persons with Disabilities	76
Exercise of Rights and Non-discrimination Provisions	76
Quota System for Employment, Stimulations and Sanctions for Employers	77
The Role of Employment Bureaus	78
National Employment Strategies	78
Analysis of Practice	78
Employment of Residents Inside and Outside the Institutions	80
Attitudes of the Public and Employers towards Persons with Disabilities	82
Example of Good Practice of Employment	83
Conclusion	84
ANNEX	86
Methodology	86
<u>Kosovo</u>	89
Structure and Functioning of Public Institutions in Kosovo	89
Kosovo's Population	89
Current Status of UN Convention on the Rights of People with Disabilities	89
Kosovo National Disability Action Plan	90
Terminology	90
Equal Recognition Before the Law	91
Legal and Policy Analysis	91
Equality before the Law	91
Initiating Court Procedures	91

Legal Capacity: Deprivation and Reinstatement by Court Decision	92
(Restriction of) Rights of People Deprived of Legal Capacity	93
Diminished Mental Capacity in the Penal Code	94
Guardianship Authority	94
Analysis of Practice	94
Status of Court Procedures on Legal Status Deprivation	94
Deprived Legal Capacity: Deprivation of Rights	96
Responsibilities of the Guardianship Authority	96
Enforcement of the Anti-discrimination Law	97
Conclusion	97
Independent Living and Community Inclusion	99
Legal and Policy Analysis	99
Legal Framework	99
Public Health Institutions: Structure and Functions	99
De-institutionalisation	102
Analysis of Practice	102
Medical model versus social inclusion	102
Special Institute in Shtime (SISH)	102
Restrictive Measures & Monitoring Mechanisms	106
Community-based services	107
Community-based homes	108
Planning and Strategy for De-institutionalisation	109
Non-Governmental Organizations' Contribution to the Process of De-institutionalisation	109
Administrative Grounds for New Enrolments at SISH	110
Homes for the Elderly	110
Provision of Medical Care to Residents of the SISH and Community Homes	110
Reintegration into the Community – A Path with Many Challenges	110
Social Assistance on the Grounds of Disability	111
Non-Governmental Organizations' Support for People with Intellectual Disabilities	111
Conclusion	112
Education	114
Legal and Policy Analysis	114
Changes Contained in the New Law on Pre-University Education	114
Aspiring Towards Inclusive Education	115
Special Education	116
Individual Education Plans (IEPs)	117
Improving School Enrolment	117
Analysis of Practice	118
Enrolment in Education	118
Inclusive Education at Work	118
Education at Institutions; After-School Activities	121
Individual Education Plans (IEPs)	122
Reflections on the Education System by Students with Disabilities	123

Programs for Supporting Inclusive Education in Kosovo	123
Conclusion	124
Work and Employment	126
Legal and Policy Analysis	126
Protecting and Promoting Disabled People's Right to Employment	126
Vocational Training	127
Analysis of Practice	128
Factors Diminishing Employment Opportunities for People with Disabilities	130
Rehabilitation and Employment	130
Employment Assistance from the Non-Governmental Sector	131
Conclusion	132
Annex I	134
Methodology	134
<u>Serbia</u>	137
Equal Recognition before the Law	138
Legal and Policy Analysis	138
Basis for and Effects of Deprivation of Legal Capacity and Extension of Parental Rights	138
Consequences of the Deprivation of Legal Capacity or Extension of Parental rights	139
The procedure Leading to the Deprivation of Capacity	139
Reinstatement of Legal Capacity	140
Guardianship – Procedure, Types and Roles	141
Analysis of Practice	143
Case Law in the Feld of Legal Capacity	143
Substantive Issues From the Case Law	147
Conclusion	150
Living Independently and Being Included in the Community	151
Legal and Policy Analysis	151
New Principles in Social Protection	151
Institutional Placement Under the Law	151
Family Support as a Way of Preventing Institutionalisation	152
New Community-based Services, Financing and Standards	152
Future Direction of De-institutionalisation in Law and Policy	153
Analysis of Practice	155
Analysing Government Data on Institutions for Persons with Intellectual Disabilities	155
Human Rights at Institutions	158
Financing and Investments	159
How Potential Users See Community Services in Serbia	162
Conclusion	166
Education	167
Legal and Policy Analysis	167
School Enrolment of Children with Developmental Difficulties	167

Measures for Support	168
Other Important Legal Aspects of Inclusive Education	169
Analysis of Practice	170
Studying Primary Schools' Inclusive Education Practices	171
Support Measures	172
Capacity-building	174
Survey of Parents of Children with Intellectual Disabilities	176
Education of Children with Developmental Difficulties Residing in Institutions	178
Conclusion	181
Work and Employment	182
Legal and Policy Analysis	182
Who Can Work?	182
Work Capacity Assessment	182
Affirmative Action	183
Protection and Prohibition of Discrimination	184
Special Forms of Employment	184
Future Strategic Priorities	185
Practice	186
Employing Persons with Disabilities in Practice	186
Role of the National Employment Service:	
Work capacity assessments and affirmative action measures	187
Employment on the Open Labour Market	188
Employment in Sheltered Jobs	189
Conclusion	193
Annex I	194
Methodology	194
<u>Conclusion</u>	197
Common Recommendations for the EU	199
Common Recommendations for the Country Governments	200
Recommendations for the Government of Bosnia and Herzegovina	201
Equal Recognition before the Law	201
Living Independently and Inclusion in the Community	201
Education	202
Work and Employment	202
Recommendations for the Government of Kosovo	203
Equality Recognition before the Law	203
Living Independently and Inclusion in the Community	203
Education	204
Work and Employment	204
Recommendations for the Government of Serbia	205
Equality Recognition before the Law	205

Living Independently and Inclusion in the Community	205
Education	206
Work and Employment	206
<u>Bibliography</u>	209
Bibliography – The Convention on the Rights of Persons with Disabilities	209
Bibliography – Bosnia and Herzegovina	210
Bibliography – Kosovo	213
Bibliography – Serbia	216

FORWARD

The main authors of the studies on whose basis this report was compiled are advocacy organizations: Mental Disability Rights Initiative Serbia (MDRI-S), Kosovo Mental Disability Rights Initiative (K-MDRI) and the Union of Organizations for Support for Persons with Intellectual Disabilities of the Federation of Bosnia and Herzegovina SUMERO. The report was compiled with the technical assistance of People in Need (PIN).

We would like to extend our gratitude to the many individuals and groups who provided their invaluable assistance during the creation of this report. We would like to thank Eric Rosenthal for his help in analysing international disability law, Jan Pfeiffer for his overall guidance and feedback on the individual country reports, and all the experts and partner civil society organizations who helped us with the in-country analysis. We also thank all ministries and government institutions in Bosnia and Herzegovina, Kosovo and Serbia that provided valuable information for this study. But most of all, we would like to thank all the individuals with intellectual disabilities and their families who were integral to creating this report by participating in the study, helped us shape recommendations and provided inspiration.

To them, we dedicate this report.

EXECUTIVE SUMMARY

In terms of respecting and promoting the human rights of people with intellectual disabilities in Bosnia and Herzegovina, Serbia and Kosovo, public institutions and society at large show insufficient and inadequate focus and engagement. For now, meeting the standards delineated in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) remains no more than a formal commitment on the part of the respective governments. Serbia and Bosnia and Herzegovina are ratifying parties to the UN CRPD, which upon ratification becomes a legally binding document.

An acute problem faced by all three countries participating in this project is the issue of legal capacity deprivation as contained in the relevant country's legislation. This legal issue clearly exacerbates the position of people with intellectual disabilities, as they are the most frequently subjected to this severely restrictive measure. People with intellectual disabilities who have been deprived of legal capacity very often end up confined in segregated residential institutions, without the possibility to enjoy equal and fair treatment on an equal basis with others. The Convention explicitly requires the abolition of legal provisions that make it possible to deprive someone of legal capacity, whilst demanding the establishment of systems that assist people in exercising their legal capacity through decision-making on an equal basis with others.

Nonetheless, it was found that legal capacity deprivation is widely practised in all three participating countries. Moreover, full deprivation of legal capacity is used far more often than partial deprivation, despite the fact that there is a clear legislative window for pursuing less restrictive measures in restricting capacity. There is a complete lack of alternative, less restrictive measures prior to delivering a decision on legal capacity deprivation. Over the course of previous legislative developments in these countries aimed at ameliorating the difficulties faced by people with disabilities, none of the countries showed any initiative for developing mechanisms that might help people with disabilities to preserve their decision-making capacity and, by extension, their legal capacity as well.

It is therefore imperative that all three countries, at the earliest possible time, initiate legislative changes in the area of legal capacity deprivation. The new legislation must be an enabling rather than a disabling factor, in other words, it should facilitate the each person's decision-making process without any restrictions or exceptions based on their disabled status. At the same time, there is a need for systematic efforts at increasing the understanding among public employees, in particular judges, independent court experts, social workers, teachers and health-care providers, so that the CRPD principles stressing the importance of empowerment of persons with disabilities can be acknowledged and applied at the respective institutions. Pending an in-depth reform, all safeguards must be stringently applied in court hearings, and legal capacity deprivation must be considered a measure of last resort. There must be a periodic review of all court decisions, acknowledging the needs and specifics of each case and the necessary resources for assistance in decision-making as required.

In all three countries, certain methods and activities are employed to enable people with intellectual disabilities to pursue independent community life. However, most of these are occasional models, established and run by the civil society sector, while government progress in this area remains stuck at the planning level. Placement in long-term residential institutions still remains the dominant form of care for people with disabilities. Once a child or an adult ends up in an institution, they usually remain there for the rest of their life, since reintegration in community life happens only rarely. Rehabilitative programs organized by the institution do not serve to empower residents to develop skills and abilities for integration in social life. Plans for de-institutionalisation remain vaguely defined, and the countries have yet to develop consolidated and feasible plans, nor have they allocated the necessary resources for moving this process forward. Public money is still used to build or renovate new institutional facilities. Although, as mentioned above, some forms of community-based placement have shown significant success in the reintegration of people with intellectual disabilities in community life, others have only replicated institutional culture. It is thus difficult even for community services to affirm an individual approach to people with disabilities and to incorporate social models into their operations.

De-institutionalisation is a process that will inevitably occur, and it must take into account all current residents of institutions. Alternative placement must become readily available as a matter of urgency in order to prevent further institutionalisation and to enable all people with disabilities to live an independent community life. With this in mind, it becomes necessary to develop individual plans for the community integration of all current residents, and to introduce and respect a no-acceptance policy for all current residential institutions. Community models that already exist in other countries can serve as guiding models for studying their applicability within domestic contexts. Government structures must develop a realistic and detailed schedule for de-institutionalisation, containing plans for the development of community services, the transformation of institutional resources and the closure of the current asylum-type institutions.

The educational opportunities for children and adults with intellectual disabilities remain a challenge that has not been given the necessary attention and engagement by any of the three governments. Despite the fact that the legislation of all these countries contains inclusiveness as a principle of education, practice falls significantly short of this normative proclamation. Inclusive education is usually seen as a rhetorical pledge rather than a strategic and planned engagement in attaining the prescribed standards. The process of developing an educational system that can be called inclusive is gradual and resource-consuming, yet the initial attempts made so far in the region have been unconvincing, and have delivered inconclusive results. Large numbers of children with disabilities still do not attend schools, and where they do, special schools and classes still prevail. Teachers regularly express concerns that they lack the skills to work with children with disabilities. Despite recent progress in enrolment, thus offering hope for younger generations, it is evident that most young people with disabilities do not receive any vocational training, thus failing to develop any marketable skills that might equip them for independent living.

The education system must fully adopt an inclusive approach to all children, irrespective of their abilities. The philosophy of inclusive education is based on the premise that all children attend the same facilities and learn in their peer group. Therefore, regular schools must be the first option for all children. The education system must provide children with disabilities all the necessary resources, including individual education plans tailored to their specific needs, in order to achieve the best possible performance and promote their maximum physical and intellectual capacity. Free and convenient transportation must be provided for all children with disabilities to and from school, along with other supporting structures that might increase the enrolment of children with disabilities in school. Teaching staff must be provided assistance through easily available materials and training aimed at enhancing their skills and providing them with the confidence for working with all children.

There is practically no employment of people with intellectual disabilities. People with intellectual disabilities who have been deprived of their legal capacity are automatically prevented from entering the job market, as they cannot sign a working contract, nor can they pursue working engagement. Even in cases when some form of payment for employment is provided, it is organized in a semi-formal manner, is unsustainable and provides remuneration that does not meet the minimum wage. People with intellectual disabilities are rarely employed in the private sector, and employment quotas are not respected by the private or the public sector.

Governments must consolidate and promote mechanisms for implementing their obligations in terms of the employment of people with disabilities in the public and private sectors so that the ratio of employees with disabilities is honoured – just as required by current legislation. More stringent monitoring of private employers is required, including sanctions where necessary in case of a failure to comply with the legally mandated quota and the provision of reasonable workplace adaptations. On the other hand, government institutions should set an example by employing people with different types of disabilities in various positions, especially when such a legal obligation exists. The accumulated fines paid by companies that fail to comply with the law should be used to generate innovative projects for improving access to the labour market for people with disabilities, for example through vocational training or small business grants.

In conclusion, the status of people with disabilities remains unsatisfactory in all three countries, with each country failing to meet the UN CRPD threshold for the analysed articles. People with intellectual disabilities are not treated equally before the law, are mostly placed in closed institutions, have few of

opportunities for quality education, and have no job opportunities. In all three countries, members of this group were clearly and unfairly marginalized. Government activities must be more focused and expeditious, since people with disabilities are not able to realize their rights anywhere near the level necessary for living a good life and being able to pursue their other rights.

INTRODUCTION

The UN Convention on the Rights of Persons with Disabilities equally protects people with all kinds and all levels of disabilities across the world. But, are persons with all types of disabilities truly being considered during reforms that affect them? This report examines the current status of children and adults with intellectual disabilities living in Bosnia and Herzegovina, Kosovo and Serbia by analysing the legal framework and the implementation of law in practice in these countries. These social groups have been marginalized in the Balkans for decades. People with intellectual disabilities are frequently discriminated against in general society, but are also marginalized within the field of disability advocacy. Because of their need for different forms of support and their continuous exclusion from public discussion, decision-making and processes that affect them, people with intellectual disabilities and psychosocial (mental) disabilities are increasingly vulnerable.

This report is the collaborative effort of three organizations that advocate for the rights of people with intellectual disabilities in southeastern Europe – the Union of Organizations for Support for Persons with Intellectual Disabilities of the Federation of Bosnia and Herzegovina SUMERO, the Mental Disability Rights Initiative - Serbia (MDRI-S) and the Kosovo Mental Disability Rights Initiative (K-MDRI). Regional collaboration among these organizations was organized within the Balkan Regional Network for Social Inclusion, coordinated by People in Need (PIN). Common action in the historically and culturally interconnected countries of Bosnia and Herzegovina, Kosovo and Serbia provides a unique possibility for cooperating on overcoming similar obstacles resulting in the unequal social status of people with disabilities.

Since the countries participating in this study used to be part of the same federation, their social care systems are organized in a similar manner. Under the Yugoslav regime, the dominant practice in the social protection of people with disabilities was institutional placement, with the medical model a dominant factor in treatment – professionals and the system were geared towards correcting “defects”. People with disabilities were usually placed in residential institutions, far from the eyes of the public. On the other hand, due to the complete non-existence of services people with disabilities living with their families were confined to their homes, meaning that they too were hidden from the public’s eye. As a result of the very strong stigma prevailing in society, people with intellectual disabilities were segregated, hidden and often abused. Schooling of children with intellectual disabilities was rare and if it existed, it encompassed only children with milder disabilities and was administered exclusively in the special education system, separate from their peers.

The question this study attempts to answer is: How much has the complete exclusion of persons with intellectual disabilities changed in the Western Balkan countries in the light of newly accepted human rights standards? It seems that ***political changes and ongoing reforms have had no or very little impact on these people’s status in society.***

This report aspires to shed light on the core issues in the life of people with intellectual disabilities. This is the first comprehensive overview of the enforcement of the rights of this particular vulnerable group - even disability advocates rarely focus their attention on this population and are not familiar with all the complexities faced by people with intellectual disabilities and their families. This report attempts to fill this gap. The study included legal analysis and an analysis of the practical application of four articles of the United Nations Convention on the Rights of People with Disabilities: Article 12 – Equal recognition before the law, Article 19 – Living independently and being included in the community, Article 24 - Education and Article 27 – Work and employment. While the Convention contains many more important articles on substantive rights, these particular articles were identified as being the most important for realizing the most basic needs of people with disabilities. The articles’ interconnectedness also plays a role in the actual realization of rights – for instance, in order to be able to live independently, a person must be capable of making decisions on his own life and should have the possibility of earning a living through employment. But for all this to be possible, he must have received an adequate education. For these reasons, the report describes the state of enforcement of the rights delineated in the Convention, and outlines immediate actions that must be undertaken by the government and its institutions in each of these three countries in order to move forward towards making these rights a reality.

The most significant difficulty that we encountered in preparing this report was the possibility of gathering relevant and complete data. None of the participating countries keeps reliable statistics on the number, needs and situation of people with disabilities. Even when some data exists, it is not disaggregated by the type of disability. This lack of proper data management leaves both the state and its citizens ignorant as to the effectiveness of programs and measures, in particular those aimed at people with intellectual disabilities. For this report, the data was collected by our network partners and external experts using both primary and secondary sources. The methodological approaches used by each partner in each specific country are described in more detail at the end of chapters 2, 3 and 4.

As noted above, there is a manifest lack of data for most issues pertaining to people with disabilities, and this shortcoming has been reflected in this publication as well. The general numbers of people with disabilities come from the most commonly used estimates, with other estimates coming from official government reports or documents, as was the case for the number of people living in residential institutions. The relevant legislation was found on the websites of national assemblies or official gazettes. Other pertinent resources included the work of independent human rights organizations, other NGOs, and international bodies. Primary research was also conducted wherever we decided that it was important to receive concrete data that did not already exist. People with disabilities and their families actively participated in the study, and provided invaluable input to this report.

The wealth of information contained in this report may serve as a solid indicator of what particular issues should be addressed in the further stages of these countries' social reform processes. This information will be relevant for policy makers during the reform of social services and education, as well as EU integration officials and advocates. It provides insight into the legislation and practises relevant to the four articles of the UN CRPD by comprehensively reflecting on the current status in each country and their achievements in attaining the rights delineated in this Convention. EU decision-makers will also find valuable information by receiving an overview of the situation and of the respective governments' achievements in respecting the principles of non-discrimination, the protection of vulnerable groups and social service reforms. Moreover, advocates throughout Europe may find the information contained herein useful for their own advocacy work related to the social inclusion of people with disabilities in their own countries.

This report is the joint effort of several civil society organizations, and can be used to compare and explore shared trends and opportunities for mutual support in the countries of the region. Closer collaboration among the stakeholders in the participating countries may enable them to overcome the current situation faster and more successfully, or to create the necessary infrastructure for making sure that the genuine reform of social care based on the principles of inclusion of people with disabilities will finally take place.

The first chapter introduces the context for this report – it sums up the general obligations the ratification of the Convention place on signatory countries in terms of legal capacity, community living, education and employment of persons with disabilities. It offers a summary of authoritative discussions and provides guidance on the established standards in these areas. There follows an overview of the three countries' compliance with the described standards: Chapter 2 examines Bosnia and Herzegovina, Chapter 3 examines Kosovo and Chapter 4 examines Serbia. Each of these chapters looks first at the country's legislative and policy framework in terms to the four Convention articles: To what extent has the country changed its outdated laws related to people with disabilities, and steps has it taken to be substantively compliant with the Convention? Each chapter then looks at the level of implementation of these laws – i.e., the actual practices in each country. After an overview of each article's implementation for each country, we provide a set of specific recommendations for achieving compliance with the Convention's standards. Finally, the concluding section of the report features recommendations for the European Union and for the individual countries' governments.

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

“...we achieved the goal sought by everyone, the approval of an international instrument that places the rights of persons with disabilities on an equal footing with other people and eliminates discrimination. (...) I believe that what emerged was an instrument that permits a ‘universal language’ for all those dealing with issues relating to disability to use as a road map for states and societies.”

Luis Gallegos Chiriboga

The Convention on the Rights of Persons with Disabilities (CRPD, “The Convention”), as the first human rights treaty in the 21st century opened for signatures on March 30, 2007 and entered into force on May 3, 2008. Owing to this short amount of time during which 20 states have expressed its full commitment in the form of ratification of the Convention, the Convention became the human rights treaty with the fastest entry into force. As of April 2012, there are 112 state parties to the Convention and 64 state parties to the Optional Protocol.¹

History of advocacy for a binding disability-specific human rights instrument is long, but for this purpose it suffices to say that the need for a disability-specific Convention was found in the recognition of grave violations and extreme marginalization of persons with disabilities worldwide. These conditions were a clear indication that universal treaties including, but not limited to the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) were simply not effective in enforcing the rights of persons with disabilities, despite the fact that the rights they conferred naturally apply to all persons including persons with disabilities. As repeatedly emphasized, in its 50 articles, the Convention does not introduce any new rights. It rather serves to complement the existing instruments by clarifying states’ obligations under the human rights law towards persons with disabilities.²

When explaining the Convention, it is impossible not to make a connection to the “Paradigm shift”, a concept marking a departure from the medical model of disability. The Convention fully embraces the Paradigm shift which tells that the disabling effects of disability must be moved away from focusing on the person’s impairments, to the social and environmental barriers that prevent a person from participating in the society on equal basis with others. With that approach, the persons with disabilities are becoming subjects of the law, which is also observed in the persistency of the Convention to emphasize participation of persons with disabilities in all aspects of the Convention: its implementation and monitoring, including participating in development of the compliant laws and policies.

The Convention does not provide a closed definition of disability or persons with disability, it rather indicates the minimum of those to whom the protection under it is guaranteed. According to Art.1 (2), persons with disabilities “include those persons with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” Implicit in this indication is the understanding that States may broaden the range of persons protected.³ Moreover, it should be emphasized that the rights and freedoms of persons with all types of disabilities are equally recognized and affirmed by the Convention and all its articles are to be read in view of persons with all of the above-stated types of disabilities. All the substantive articles are also to be interpreted in light of the Convention’s principles as elaborated in the Article 3. As a cornerstone of human rights law, the prohibition of discrimination is contained and persists throughout the Convention. The prohibition extends to all

¹ Optional Protocol to the Convention on the Rights of Persons with Disabilities acknowledges the justiciability of the rights contained in the Convention, or in other words, enables complaints (individual communications) to be filed against the state party by the person who considers their Convention-guaranteed rights to be violated by the said state.

² The secretariat for the Convention on the Rights of Persons with Disabilities-DES, OHCHR & The Inter-Parliamentary Union: From Exclusion to Equality: Realizing the Rights of Persons with Disabilities - Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol, 2007, p.20

³ Ibid, p.13

forms of discrimination (except for the affirmative measures) including denial of reasonable accommodation, which is defined as: “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden” and necessary for the person’s enjoyment of rights on equal basis with others.

In terms of obligations for state parties, those are of the same nature as under the other human rights treaties: the obligations to respect, protect and fulfill. The general obligations are provided as a non-exhaustive list of specific actions in Article 4 and include: modifications and abolishment of laws, customs and practices which constitute discrimination against persons with disabilities (Art.4.1.b), refraining from practices which are inconsistent with the Convention (Art.4.1.d), undertaking measures to eliminate discrimination on basis of disability by private entities (Art.4.1.e), undertaking or promoting research and development of new assistive technologies, universal design and similar (Art.4.1.f & Art.4.1.g), training of relevant professionals on the Convention (Art.4.1.i) etc.

The obligations are further elaborated in each of the articles which are categorized after particular spheres of life. It is worthy to note that all these articles specifying particular rights and freedoms are tightly interrelated and cannot be looked at in vacuum. Their realization depends on the realization of all other rights and freedoms, but also on the engagement of the elaborated Convention principles. Following is a short overview of the four such articles of the Convention: Article 12 (Equal recognition before the law), Article 19 (Living independently and being included in the community), Article 24 (Education) and Article 27 (Work and employment).

Article 12 - Equal Recognition Before the Law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

“Legal capacity (...) refers to an individuals’ right to make decisions – big and small – for him/her self and have those decisions respected. When a person’s capacity to make decisions is called into question (on the basis of mental illness, intellectual disability, acquired brain injury, or other reason) the state should make available a range of responses appropriate to the needs of the person. However, the reality is that States have failed to remove significant legal barriers that prevent people with disabilities and others from making their own decisions. Legal capacity is often routinely restricted or completely denied.”

Prof. Gerard Quinn

Importance and Development

Article 12 is the embodiment of the paradigm shift – the approach where focus is placed on a person as a subject, rather than the same person being treated as an object to be managed. This is so because it sets the framework for decision-making and its legal effects, or in other words, it talks

to the capacity of persons with disabilities to act. Precisely that is the reason why it is frequently regarded as “the core” or “capturing the revolution of ideas which CRPD promotes”: Dhanda, for example says that analysis of this right, more than of any other one “will show how the Convention challenges stereotypes surrounding disability”.⁴ The Article applies the non-discrimination principle to challenge the deepest prejudice on the effects of disability on the capacity of persons.

The above text of the Article was a result of a fierce debate during the drafting process and to this day remains one of the most analyzed and discussed articles of the Convention. The many declarations and reservations the states raised in view of it, prove to show ambiguities in understanding its content.⁵ Quinn states that the Article was devised with a degree of such ambiguity on purpose, to bring the reluctant states along.⁶ Notwithstanding these ambiguities, a body of opinion has formed since the drafting process to today, which bring us to conclude with certainty that the Article 12 offers a completely new approach to models of capacity of persons with disabilities.

Authoritative Opinions

The opinio juris is best noted in the interpretation of obligations by the Committee on the Rights of Persons with Disabilities (“the Committee”),⁷ evident in the adopted concluding observations in view of the up-to-date state reporting. In its first concluding observation on Tunisia’s report, the Committee expressed its concern that no measures have been taken to replace substitute decision-making by supported decision-making in the exercise of legal capacity:

The Committee recommends that the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making. It further recommends that training be provided on this issue to all relevant public officials and other stakeholders.⁸

The second time – in view of the Spain’s initial report, the Committee underlined its previously expressed concerns and emphasized that the supported decision-making regime is to respect the person’s autonomy, will and preferences.⁹ While it certainly became clear from the Committee’s interpretation that guardianship as substitute decision-making model is in contravention with the Article 12, this early stance of the Committee falls short of providing guidelines to states on the implementation of the Article. Considering the short existence of the Committee, it is probable that this lack of clarity will be remedied through its future work, primarily General Comments and individual communication mechanism.

Other human rights bodies undertook a strong stance on the Article 12 as well. For instance, the UN Office of the High Commissioner for Human Rights stated:

In the area of civil law, interdiction and guardianship laws should represent a priority area for legislative review and reform. Legislation currently in force in numerous countries allows the interdiction or declaration of incapacity of persons on the basis of their mental, intellectual or sensory impairment and the attribution to a guardian of the legal capacity to act on their behalf. Whether the existence of a disability is a direct or indirect ground for a declaration of legal

⁴ Amita Dhanda: Legal capacity in the disability rights convention: Stranglehold of the past or lodgestar for the future? Syracuse J. Int’l L. & Com. Vol. 34:429, p.430

⁵ Canada, Egypt, Mexico, Syria, The United Kingdom

⁶ Statement by Professor Gerard Quinn, Director, CDLP to the Oireachtas Joint Committee on Justice, Defence and Equality: Hearing on the Mental Capacity Bill, (29 Feb 2012), p.7 available on http://www.nuigalway.ie/cdlp/documents/cdlp_statement_to_oireachtas_justice_committee_on_mental_capacity_bill_final.pdf

⁷ The Committee is the authoritative body for the Convention; its mandate and primary task is monitoring implementation of the Convention through consideration of state reporting and of individual communications, with provision of its observations and recommendations.

⁸ Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities on Tunisia’s initial report; CRPD/C/TUN/CO/1, Fifth session, 13 May 2011, para 23

⁹ Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities on Spain’s initial report; CRPD/C/ESP/CO/1, Sixth session, 19 October 2011, para 34

incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2.¹⁰

The Council of Europe's Commissioner for Human Rights, Thomas Hammarberg has issued a position paper in which it argued that Article 12 is both evolutionary and revolutionary:

It is evolutionary in that it builds on best practices developed in some countries in close cooperation with the disability movement and encourages reform. The revolution – or the paradigm shift – of Article 12 is probably not quite precise about the ultimate shape European legal capacity law should take but it is clear enough to enable us to characterise the bulk of European legal capacity systems as out-dated. It compels law reform to assume that everybody enjoys legal capacity and redirects our focus away from deficiencies (which are in fact universal and not confined to persons with disabilities) towards supports that enable individuals to make decisions for themselves and expand their capacities to do so.¹¹

Finally, the Council of Europe's European Court of Human Rights (ECtHR) has developed a substantial case law on legal capacity of persons with disabilities. While not yet adopting the revolutionary approach, the ECtHR has confirmed several times in its judgments that it considers deprivation of legal capacity to be a serious measure requiring utmost scrutiny: "(...) the Court would like to stress once again that strict scrutiny is called for where measures that have such adverse effect on one's personal autonomy are at stake. In this connection the Court is mindful that divesting someone of legal capacity entails grave consequences for various spheres of that person's life."¹² Moreover, the ECtHR makes a crucial distinction between provision of care and respecting the autonomy of persons in need of assistance:

(...) the Court stresses that it is legitimate to provide care for the sick or elderly, or persons with diminished capacity who are unable to care for themselves. It is, however, an entirely different thing to deprive someone of legal capacity (...) In order to ensure that the sick and elderly are properly cared for, the State authorities have at their disposal other means than divesting such persons of their legal capacity.¹³

In making a distinction between depriving someone of their capacity and taking care of persons who are unable to care for themselves, ECtHR clarifies that depriving a person of their recognition under law cannot be justified under the excuse of care or protection of the person and that "care" in fact demands some other, different measures. Importantly, the Court is directly invoking the Convention and the Article 12 in its analysis, which is indicative that its future approach will be on track of the Committee itself.

Legal Context of Decision-making

When discussing what the Article 12 specifically prescribes and how it translates to the reality for persons with intellectual disabilities, it is necessary to provide a wider context. Looking at disability law that constructs incapacity across jurisdictions worldwide, legal scholars concluded that three approaches to incapacity determination exist: status attribution, outcome test and functional test.¹⁴ The first model, status attribution is where law assumes lack of capacity because a person has an

¹⁰ U.N. Office of the High Commissioner of Human Rights, Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, para 45, U.N. Doc. A/HRC/10/48 (26 January 2009)

¹¹ Right to legal capacity for persons with intellectual and psychosocial disabilities [CommDH/IssuePaper(2012)2], Strasbourg, 20 Feb 2012, available on <https://wcd.coe.int/ViewDoc.jsp?id=1908555>

¹² X and Y v. Croatia, no. 5193/09, para 109; 102-104; similar wording also in: Sthukurov v. Russia (no.44009/05, para 71), Salontaji Drobnyak v. Serbia (no. 36500/05, para 140 et seq), Stanev v. Bulgaria (no. 36760/06, para 241) Very significant is also the Court's finding that "...if a restriction on fundamental rights applies to a particularly vulnerable group in society, who have suffered considerable discrimination in the past, such as the mentally disabled, then the State's margin of appreciation is substantially narrower and it must have very weighty reasons for the restrictions in question.", Kiss v. Hungary (no. 38832/06, 20 May 2010), para 42

¹³ X and Y v. Croatia, no. 5193/09, para 90 & 91

¹⁴ Dhandu, see *ibid* ad 4, p.431-433; also in Amicus Brief in the European Court of Human Rights, in the case of D.D. v. Lithuania, Application No 13469/06, by the European Group of National Human Rights Institutions, April 2008; and in Written submission pursuant to Rule 44(4) of the Rules of Court of the European Court of Human Rights, in the case of D.D. v. Lithuania, Application No 13469/06, by the Harvard Project on Disability

intellectual, psychosocial or physical disability. This is a pure medical model where judges serve only to ensure that ascription of disability and thereby incapacity does not take place without the due process. The outcome test is based on the premise that where a person has made “wrong” decisions in the past, s/he needs to be deprived of capacity to make decisions. This model sets a double standard since no similar test exists for persons without disabilities – they are free to make as many bad choices as they please, without that resulting in restriction of their legal capacity. The functional test does not take disability status as the only criteria, but adds a person’s inability to perform a function as a result of disability. It recognizes that capacity is time-specific and issue-specific.

The Council of Europe’s Commissioner for Human Rights Thomas Hammarberg analyses these approaches from the Convention’s standard:

All of these approaches are objectionable. The status approach rests on stereotypes and ignores the person’s actual abilities. The outcome approach is contradictory and does not afford persons with disabilities the dignity of making mistakes and taking risks like the rest of us. The functional approach has, so far, given too little attention to the importance of support. The functional approach may yet have a future, not as a yardstick by which to withdraw capacity as in the past, but rather as a measure to help determine what type of supports should be made available to the individual.¹⁵

Deconstructing the Obligations

Art.12(1) states that persons with disabilities are recognized as persons before the law or in other words, they have capacity to hold rights. Art.12(2) supplements this guarantee by mandating persons with disabilities the right to act on the rights established in 12(1), or in other words, the right to enter agreements which would give effect to their will and intentions. The Art.12(2) is also known as “the right to act”, and has been the main point of controversy in interpretative discussions on the Article 12.

Art.12(3), devotes due attention to the supports required. Yet, it does not develop this issue further, to the concrete level thereby leaving decision-makers uninformed on the nature of supports and how those function in everyday life. Bach gives a very helpful analysis of what individual supports should encompass in order to set-up decision-making systems which are conducive to the Convention’s principles and objectives.¹⁶ It encompasses, but is not limited to: informal assistance of family and friends, assistive and adaptive communication means, representatives and networks for assisting in decision-making (implicating developing systems for registering, monitoring and mediation), advance directives, support to third parties in relations with a person, protections from liability for assistants etc.

Art.12(4) talks about safeguards, thereby motivating the opponents of a paradigm shift to pose a question whether specifying safeguards, which were inherent in the old guardianship model, serves as legitimization of the substitute decision-making. The truth is however that safeguards are not applicable only in substitute decision-making models – even the least restrictive models must retain procedural guarantees which would ensure that the will of a person is respected, and that the supportive networks do not overstep their competences. On the other hand, it should be recognized that some persons, due to lack of social ties and severity of the effects of their disability, are not going to be in a position to express their intent to act. In reality this small percentage of persons¹⁷ will probably require someone else making decisions on their behalf. The Article does not explicitly state that circumstances will exist where a complete lack of capacity will occur, but it also does not exclude possibility that some substitute form of decision making may be utilized in exceptional cases. Still, it must be borne in mind that, within the context of the Article and the whole Convention, this can take place only as a last resort – and importantly, not excluding the obligation under the Art.12(3) which continues to apply.

¹⁵ Hammarberg, see *ibid* ad 11

¹⁶ Bach, Michael, Canadian Association for Community Living & Inclusion International: The Right to Legal Capacity under the UN Convention on the Rights of Persons with Disabilities: Key Concepts and Directions for Law Reform, October 2009, p.12

¹⁷ Prof. Quinn estimates those persons to make-up approximately 5% of all persons with disabilities who are to benefit from the positive capacity legislation. In Quinn, Gerard: Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD, HPOD Conference, Harvard Law School (20 Feb 2010), p.10

Inclusion of the special provision on the right to property in the form of Art.12(5) serves to emphasize the recognition of a widespread abuse of rights in financial matters for persons with disabilities, frequently connected to legal capacity deprivations.

Conclusion

Despite the in-depth analysis of the rights and guarantees inherent in the Article 12, it may remain a challenge for the legislators to devise a Convention-friendly law on legal capacity. Of crucial importance is that law and policy serve not to impede persons including those with intellectual disabilities, but that they are geared towards creating opportunities for them to grow and develop.¹⁸ With respect to the states' discretion in devising national systems, some key concepts which national laws should contain in order to be compliant with the CRPD's approach to capacity, have been identified.¹⁹ Principles such as presumption of capacity, correct balance between respecting autonomy and protection, detachment from the patronizing "best interest", social model, the right to take risks and the right to accessible information should be embedded in capacity laws.

Article 19 Living Independently and Being Included in the Community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

"The need for support does not justify inhibiting or regulating people with disabilities in a way in which people without disabilities are not regulated."

Thomas Hammarberg

Value and Importance

Article 19 is frequently described as the "core" or of "critical importance" to the Convention and rightly so, since independent living as a concept implicates viability of all other rights prescribed in the Convention. For a person to be able to live independently they need to be able to make decisions about their own life, they need to have an accessible environment, to receive compensation for their work, to receive adequate support in form of community services etc. In other words, living independently and being included in the community is closely linked with other human rights such as equality and non-discrimination, physical and mental integrity, liberty, freedom from inhuman or degrading treatment or punishment, autonomy, legal capacity, privacy, family rights, and freedom of movement.

It is crucial to develop an understanding of this article as a right which is tightly interlinked not only with other rights in the Convention, but with the paradigm shift itself. This is so because as many actors recognize, misunderstanding this right leads to risking the replacement of one type of exclusion

¹⁸ Dhanda, see *ibid* ad 4, p.458

¹⁹ As defined in analysis of proposed legislation on legal capacity in Ireland by the Centre for Disability Law and Policy: The Centre for Disability Law and Policy, NUI Galway: Submission on Legal Capacity to the Oireachtas Justice Committee on Justice, Defense & Equality (Aug 2011)

with another. This is apparent from the practice - even though unavailability of the process of deinstitutionalization is gradually becoming clear to most governments, they are still perplexed about the alternative forms which are to be put in place.²⁰ In developing supports to replace the institutional placements, states sometimes neglect the equality and human rights principles which are core to the paradigm shift, making it all too easy to disregard the effective change that needs to happen.

Deconstructing Obligations

Article 19 clearly states that unjustified segregation of persons with disabilities in institutions is a human rights violation in itself.²¹ Whereas a myriad of evidence speaks of the dehumanizing and abusive nature of institutional care, the objection to institutions is equally founded on the premise that personal autonomy cannot be realized within the institutional setting regardless of the physical conditions or care practices. Grouping users in institutional care on the basis of their disability and provision of block treatment contradicts the principle of the respect for dignity and autonomy of an individual with a disability. Additionally, as noted by Hammarberg, grouping people together already sets them apart from society as a group of their own and it is drawing the community's gaze to disability. In this respect, he asserts, grouping people with disabilities together is not in line with the positive obligation of promoting positive perceptions towards persons with disabilities.²² Having all this in mind, it needs to be emphasized that the improvement of conditions and services within the institutional setting fails to achieve the standard provided by Article 19 aimed at securing the community inclusion of persons with disabilities. This argument should be devoted sufficient attention to when devising a state policy towards care of children and adults with disabilities and particularly when allocating domestic and foreign funding.

Article 19(a) talks about the choice of a person regarding their place of residence. Authorities are sometimes quick to defend existence of institutions based on the argument that they are a personal choice for residence of a number of persons. Hammarberg argues however that institutions are not an option where "choices equal to others" can be practiced "because life in institutions severely inhibits the possibility of activating one's choice, even in the most basic way".²³

Article 19(b) provides evidence to this end stating that support services must be in community and such as "to prevent isolation or segregation from the community". This is a standard which applies equally to all persons with disabilities regardless of their type or severity. Therefore, this qualifier implicates that services must pay close attention to the persons with high needs for supports. If such persons remain isolated in their homes without services which enable them to engage in meaningful interaction with the community, this provision is not satisfied.

Article 19(c) mandates that all services for general population are accessible to all persons with disabilities. While this unquestionably refers to physical and infrastructural barriers, barriers of the administrative and communication nature are often overlooked, yet they are equally important. Community services must be open on equal basis to persons with all kinds of disabilities.

Segregation from society on the basis of disability, constitutes discrimination under the CRPD. The protection against discrimination is the unifying principle upheld throughout the CRPD and provides much more detailed protections against discrimination to persons with disabilities than mainstream human rights instruments such as the European Convention on Human Rights (ECHR). But, besides implicating the denial of the right to community living, segregation on basis of disability also entails the denial of a broad deprivation of a person's ability to exercise all other rights such as the right to life, right to health, right to habilitation and rehabilitation. Disability Rights International asserts that such extensive violations of the rights of persons with disabilities under the CRPD can be used as evidence to demonstrate discrimination under the general regional human rights instruments, for example such as the ECHR.²⁴

²⁰ The right of people with disabilities to live independently and be included in the community [CommDH/IssuePaper(2012)3], Strasbourg, 13 March 2012, available on <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

²¹ Parker, Camila: An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities in European Coalition for Community Living: Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities, p.23, 2009

²² Hammarberg, see *ibid* ad 20, para 3.2.2.

²³ Hammarberg, see *ibid* ad 20, para 3.1.1.

²⁴ Disability Rights International and Comisión Mexicana de Defensa y Promoción de los Derechos Humanos: Abandoned and Disappeared: Mexico's Segregation and Abuse of Children and Adults with Disabilities (Nov 2010, updated Jun 2011), p.35

Timing of Obligations

It is crucial however to note that the right to independent living, alongside its socio-economic nature, also contains a civil and political aspect having an impact on the nature of the states' obligations in view of the realization of the right to independent living. This suggests that the right is not fully susceptible to progressive realization. For example, the civil and political aspect is perhaps most evident in choosing one's own place of residence – 19(a), a right which, while it implicates the existence of variety of choices – as specified in 19(b), stresses the essence of person's decision-making. There is certainly an immediate requirement to enforce the obligation not to encroach upon each individual's right to decide on a place of residence. Based on this, it may be argued that this provision would challenge a common practice of the authorities placing persons with intellectual disabilities into homes without obtaining those persons' opinions and without undertaking specific steps to ensure their wish is given effect.

Despite the fact that institutional care cannot be replaced with community care overnight, an explicit commitment by the state, including a plan of action is a necessary first step to meeting the obligation of closing institutions for persons with disabilities which is intrinsic to the Article 19.²⁵ Closely tied to this, it is implicated that investing funding into forms of care which do not support the right to community living, i.e. forms which place obstacles to the active involvement of persons in their society, would represent a violation of the Convention. Firstly, the negative obligation of the state exists to refrain from supporting solutions which do not give effect to the rights contained in the Convention ("deliberately retrogressive measures would require the most careful consideration and would need to be fully justified by reference to the totality of the rights provided for in the Covenant").²⁶ Secondly, this would mean that the available resources are not placed to their full use or "in an effort to satisfy, as a matter of priority, those minimum obligations."²⁷ Consequently, it may be argued that the obligation of investment of resources into community living is of an immediate nature.

Authoritative Opinions

The Committee has not yet had an in-depth look into the interpretation of Article 19 and the reasonable accommodation it requires. Nonetheless, in its Concluding Observations regarding Spain's initial report, the Committee expressed its concern: at the lack of resources and services to guarantee the right to live independently and to be included in the community, in particular in rural areas; that the choice of residence of persons with disabilities is limited by the availability of the necessary services; and that persons in residential institutions do not have an alternative to institutionalization.²⁸ While it has used mild language to encourage the state to ensure adequate funding for the realization of Article 19, the Committee did not hesitate to raise a specific issue of inaccessibility of support services to all persons with disabilities. Specifically, the Committee's remark was directed at legislation's linking eligibility of social services such as resources to hire personal assistants to a specific grade of disability.²⁹ As a result, the Committee encouraged the state to "expand resources for personal assistants to all persons with disabilities in accordance with their requirements."³⁰

The Council of Europe's Commissioner for Human Rights, Thomas Hammerberg's opinion on the right to live in the community has been cited throughout this section. His opinion on the future that is mandated by this Article is firm:

While monitoring closed settings is critical to minimising abuse within those settings, no amount of monitoring or closed-circuit TV cameras can rid institutions of their susceptibility

²⁵ Open Society Mental Health Initiative: A Community for All: Implementing article 19, A Guide for Monitoring Progress on Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities, Dec 2011, p.17, available on http://www.soros.org/initiatives/health/focus/mhi/articles_publications/publications/community-for-all-20111202/community-for-all-guide-20111202.pdf

²⁶ UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant), 14 Dec 1990, E/1991/23, para 9

²⁷ Ibid, para 10

²⁸ Concluding observations – Spain, see *ibid* ad 9, para 39

²⁹ *ibid*, para 39 & 41

³⁰ *ibid*, para 42

to situations of abuse. The solution lies in dismantling these facilities, and developing more humane community-based services.

As for the other services provided to persons with disabilities, Hammarberg states that:

The central authorities have a duty under international law to ensure that even services run by local or municipal governments do not discriminate, because the State has a duty “to ensure that public authorities and institutions act in conformity with the [CRPD]” (Article 4(1)(d) of the CRPD).

Conclusion

Article 19 has been a strong focus of advocates precisely because of the persistence of institutional systems in most countries in the world. Despite the fact that Article 19 does not explicitly call for closure of institutions, accumulated opinion proves that this is an obligation inherent in the article. In planning for transformation from institutional to community care, the criteria of the progressive realization must not be disregarded, as well as the fact that certain obligations are of an immediate nature. Those are, for example, the right of persons with disabilities to choose their place of residence and where and with whom they live as well as freedom from discrimination in provision of services, which has already been directly addressed by the Committee.

Article 24 Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:
 - (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
 - (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
 - (c) Enabling persons with disabilities to participate effectively in a free society.
2. In realizing this right, States Parties shall ensure that:
 - (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
 - (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
 - (c) Reasonable accommodation of the individual's requirements is provided;
 - (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
 - (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.
3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
 - (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
 - (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
 - (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and

alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

“Education builds resilience to, and pathways out of, poverty and disadvantage. Education also provides persons with disability with the means of gaining the knowledge and skills necessary for civic participation and to effect social change. Education also plays an important role in social development and interaction, often the avenue for life-long friendships and support networks.”

Rosemary Kayess

Importance and Development

Due to the overarching impacts of education on a person's future and possibilities, it might well be said that the right to education represents a cornerstone of the socio-economic rights. The right to education is an old right initially established with the Universal Declaration on Human Rights (UDHR) in 1948. At the time, inclusive education was unknown as a concept. Nevertheless, with time, subsequent international human rights instruments became more concrete about what the education system should be like. Through both binding and soft law, the right to education seemed to elaborate more on the purpose and role of education thereby indicating a move towards the concept of inclusive education.³¹ Placing an emphasis on the need for education to enable the students to fully and effectively participate in the society has further instructed the states on obligations in terms of form and quality of education, and hence paved the way for inclusive education in international law. Without expressly mentioning inclusion, the international soft law further developed the concept through identifying obligations in the form of four standards to which the educational system must conform: availability, accessibility, acceptability, adaptability (the four As). In short, these standards mandate that: education must be provided (availability), there should be no physical, economic or socio-cultural obstacles to accessing it (accessibility), it should be relevant, culturally appropriate and of good quality (acceptability) and it should respond to a child's needs (adaptability).³²

Nowadays, Article 24 is also known as the 'right to inclusive education' which connotes the transformation of the above concepts into binding law. The states have an obligation to ensure the existence of an inclusive educational system on all levels. It implies the acknowledgment by the system of the fact that every child is unique and that each child notwithstanding specific learning needs must be attended to by the educational system. In the context of disability, that means that every child must have access to education regardless of the nature or level of disadvantage that affects them. On the other side of the non-discrimination coin is the obligation to provide reasonable accommodation to accommodate a disability. In other words, the curricula, teaching methods, testing methods, learning materials, buildings and assistive technologies have to become child-centered and adapt to the needs of each individual child.

Core Dilemma

Ever since the drafting process and still nowadays, the most contentious issue in relation to Article 24 has been the issue of the existence and future of the special education system. The crux of the controversy may be described as a collision of the polarizing attitudes - on one side arguing that the best interest of a child may require a special learning environment where a child is surrounded with peers who experience the same challenges, and on the other side, arguing that any provision of separate education constitutes inequality which is prohibited by the Convention.

³¹ Report of the Special Rapporteur on the Right to Education (Vernon Munoz), The Right to Education of Persons with Disabilities, UN doc. A/HRC/4/29, 19 February 2007, para 17

³² UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 13: The Right to Education (Art. 13 of the Covenant), 8 Dec 1999, E/C.12/1999/10, para 6

Unfortunately, it is not possible to elaborate in-depth on this discourse. Still, it is worthwhile to illustrate the core of the argumentation coming from both sides. As the Special Rapporteur on the right to education concludes, “The special schools, often based on the belief that persons with disabilities are uneducable and a burden on the mainstream educational system, often were – and remain – inflexible, non-individual-student specific and they fail to provide or even offer optimum results for their students.”³³ On the contrary, some representative groups argue that in order to ensure equality, it is necessary to facilitate equality in language and literacy instruction which has to take place in a segregated environment.³⁴

In answering to demands that call for a child’s (parents’) right to choose whether to attend segregated education, many advocates justly argue that “the right to choose” approach raises an apparent incompatibility of promoting inclusion while at the same time supporting two contradictory concepts – inclusion and exclusion. The problem is compounded by the fact that inclusion and exclusion are mutually exclusive, as it can be established that when one occurs the other does not. Legitimizing the choice of exclusion would make it seem as if inclusion is optional. Additionally, the right to choose implicates the state’s obligation to develop (or retain) two separate educational systems which is economically unfeasible for many countries and is also a realistic threat to the development of a fully inclusive mainstream system. Beyond the economical and practical issues however, it should be noted that proponents of the right to choose in arguing that provision of separate education is necessary to provide equal opportunities comply with the separate and equal doctrine.³⁵

Deconstructing Obligations

Despite the fact that the text of the Article remained silent on this issue, the Convention indeed attempts to resolve the issue. The Article requires states to develop a mainstream education system which is inclusive, but it does not specify an obligation to cease operating special school systems. It is clear however that the inclusiveness is heavily emphasized throughout the Article and that the wording of the Art.24.3.c is construed in a way as to ensure this is only a tight exception to the general rule and that applies to children with sensory disabilities only.³⁶

The Article does not specify the exact obligations in terms of reasonable accommodation i.e. which exact assistance a state needs to provide to a child with disability to ensure their inclusion and failure of provision of which assistance would constitute discrimination on basis of disability. While Article 24 gives quite detailed indications as to what the concrete obligations are, it remains to be established, probably through case law or the Committee’s general comments what the threshold of discrimination is when a child is not provided reasonable accommodation in order to be able to practice the right to education.

Authoritative Opinion

The Committee in the case of Tunisia, expressed its “deep concern” that the inclusive strategy is not equally implemented in mainstream schools and that rules regarding numbers of children with disabilities in classes are commonly breached. It found itself equally concerned that mainstream schools are not equipped to receive children with disabilities and emphasized training of school staff as a significant issue.³⁷ The second time, in case of Spain, the Committee was more elaborate, foremost in its concern about “continued segregation and exclusion” and the lack of a possibility to appeal placement of their children with disabilities in special education. But significantly, the Committee also

³³ Report of the Special Rapporteur on the Right to Education, see *ibid* ad 31, para 11

³⁴ Mostly argued by the groups of persons with sensory disabilities, in Centre for Studies on Inclusive Education: Article 17 and inclusive education in the new UN Disability Convention: Briefing from the Centre for Studies on Inclusive Education, (Aug 2004) available at www.un.org/esa/socdev/enable/rights/csiecontribahc4.doc

³⁵ This doctrine has been declared unconstitutional in a famous judgment which stopped racial segregation in the US. The judgment *Brown v. Board of Education* (1954) stated that separate educational facilities are inherently unequal: “Segregation of white and colored children in public schools has a detrimental effect upon the colored children. The impact is greater when it has the sanction of the law, for the policy of separating the races is usually interpreted as denoting the inferiority of the negro group. A sense of inferiority affects the motivation of a child to learn.”

³⁶ Quinn, Gerard: Disability and Human Rights: A new field in the United Nations, in Kruuse, C. & Scheinin, M., (Eds), *International Protection of Human Rights, a Textbook*, (Institute for Human Rights, Abo Academie University Finland, 2009), p.267

³⁷ Concluding observations – Tunisia, see *ibid* ad 8, para 30&31

touched upon the implementation of the concept of reasonable accommodation in education. It reiterated that “denial of reasonable accommodation constitutes discrimination and that the duty to provide reasonable accommodation is immediately applicable and not subject to progressive realization”.³⁸ In more detail, clarifying some measures which constitute the reasonable accommodation in view of the right to education, the Committee calls Spain to:

Increase its efforts to provide reasonable accommodation in education, by: allocating sufficient financial and human resources to implement the right to inclusive education; paying particular attention to assessing the availability of teachers with specialist qualifications; and ensuring that educational departments of local governments understand their obligations under the Convention and act in conformity with its provisions.³⁹

The Committee also emphasizes that states must ensure that the costs of measures of reasonable accommodation in mainstream schools do not fall on parents of children with disabilities.⁴⁰

Additionally, the Committee devoted attention to special education systems and clarified some of the state obligations in this regard. It specified that the state must not only “ensure that the decisions to place children in a special school or in special classes, or to offer them a reduced-standard curriculum, are taken in consultation with the parents; but it must also ensure that such “decisions on placing children in segregated settings can be appealed swiftly and effectively”.⁴¹

Conclusion

The text of Article 24 is rather clear that establishment of inclusive mainstream education is a mandated obligation without which the right to education of a child with a disability cannot be realized. The initial authoritative interpretations by the Committee serve to further clarify the two most contentious issues. As far as reasonable accommodation that is to be provided to children with disabilities in mainstream schools is concerned, it is not subject to progressive realization, but is of immediate effect and failure to provide it constitutes discrimination based on the disability of the child. Of great importance is that such measures must be free and not imposed on parents. On another note, admissions of children into special schools need to be under strict scrutiny by the authorities; parents must provide their informed consent and must not be pressured into enrolling their child into a special school or a special class. Decisions to enroll children in special schools, must be of a quickly reversible nature.

Article 27 Work and Employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
 - (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
 - (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
 - (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

³⁸ Concluding observations – Spain, see *ibid* ad 9, para 43&44

³⁹ *Ibid*, para 44(a)

⁴⁰ *Ibid*, para 44(c)

⁴¹ *Ibid*, para 44(b)& 44(d)

- (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
 - (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
 - (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
 - (g) Employ persons with disabilities in the public sector;
 - (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
 - (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
 - (j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
 - (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

“...more energy is required to change social attitudes so that people recognize that as full members of society, we have the right to work to support ourselves and our families as do all other members of society.”

Ron McCallum,

Chair of the Committee on the Rights of Persons with Disabilities

Value and Importance

It has been estimated that in most countries the unemployment rate among persons with disabilities is two to three times higher than the unemployment rate for persons without disabilities. Where persons with disabilities are employed, they are mostly engaged in low-paid jobs with little social and legal security and are often segregated from the mainstream of the labour market.⁴² But it must also be noted that, even for disability-related programs that address this issue of high unemployment, it has been recognized that persons with certain types of disabilities such as intellectual disabilities, do not benefit to the same degree as persons with other disabilities.⁴³

Article 27 is in essence an equal opportunity right of a non-discriminative nature with prescribed reasonable accommodation. It specifies in a very sharp detail what is meant by “the right to work”. While it certainly requires opening of the labour market for persons with disabilities and introducing affirmative action measures for their employment, the right to work is much more than this.

Deconstructing Obligations

Article 27 requires that states undertake steps including legislative measures to prohibit discrimination against persons with disabilities in their recruitment, job retention, work conditions, benefits and compensation and promotion. Prohibition of discrimination besides its negative obligations implies the positive ones in terms of provision of reasonable accommodation which is specifically addressed under Art.27.1.i. One of those reasonable accommodation measures can be found in Art.27.1.e which mandates assistance in finding, keeping and returning to employment (supported-employment model). Use of the term “returning to” in this provision serves to emphasize that the right to employment under the Convention applies equally to persons who are about to enter the labour market and persons who have been excluded from it. Therefore, the state has an obligation to ensure that even long-excluded persons with disabilities can practice their right to employment. The state

⁴² UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 5: Persons with Disabilities, 9 Dec 1994, E/1995/22, para 20

⁴³ Background paper for Informal Session on Work and Employment, Note by the Secretariat, CRPD/CSP/2011/CRP.4, Fourth session of the Conference of State Parties to the Convention on the Rights of Persons with Disabilities (New York, 7-9 Sep 2011)

also has a clear responsibility to protect persons with disabilities from any harassment at work place as affirmed in Art.27.1.b.

A very important role of the state under the Article 27 is promotion of employment of persons with disabilities through their employment in the public sector and adoption of policies to facilitate their employment in the private sector. Additionally, promotion must be done through enabling persons with disabilities to develop entrepreneurship and self-employment. The Article recognizes that for effective access to employment of great importance are both formal and informal education and skills. Hence Art.27.1.d mandates access to general technical and vocational guidance programs, placement services and vocational and continuing training. The concept of employment on an equal basis with others and significance of participation is strengthened by provision Art.27.1.c which calls for the exercise of labour and trade union rights of persons' with disabilities on an equal basis with others.

Finally, Art.27.2 recognizes that practices around the world exist where persons with disabilities are forced to perform certain work tasks often in conditions which could well be found to violate their dignity as human beings. Quinn argues that this provision provides space for the Committee to scrutinize the existence of "many of the egregious practices of sheltered workshops." It is argued that in addition to freedom "from forced or compulsory labour", other standards provided by the Article 27 such as "just and favorable conditions of work", "equal remuneration for work of equal value", as well as protection "on an equal basis with others" will have the strength to challenge sheltered workshops as the dominant form of working engagement for persons with intellectual disabilities.⁴⁴ In support of this, the General Comment No. 5 affirmed that: "The 'right of everyone to the opportunity to gain his living by work which he freely chooses or accepts' (art. 6 (1)) is not realized where the only real opportunity open to disabled workers is to work in so-called 'sheltered' facilities under substandard conditions" and that "Arrangements whereby persons with a certain category of disability are effectively confined to certain occupations or to the production of certain goods may violate this right".⁴⁵ Moreover, the "therapeutical" treatment that is often administered in institutions for persons with intellectual and psychosocial disabilities may amount to forced labour.⁴⁶

Authoritative opinion

The Committee has referred to the right to work and employment in light of concern at the low rates of employment of persons with disabilities. It took note of the enabling provisions and the states' efforts to employ persons with disabilities in public sector, but emphasised that its attention is directed at the private sector employment.⁴⁷

In light of this, the Committee recommended that the states ensure the implementation of the legal provisions of affirmative action, that they diversify employment and vocational training programs and that they ensure participation of persons with disabilities in relevant state bodies.⁴⁸ Also, the Committee recommended that the programs for increasing the employment of persons with disabilities be "open and advanced".⁴⁹

Although the Committee has not directly expressed its standpoint towards the sheltered employment, the CoE Commissioner for Human Rights has been quite clear in its issue paper on the right to community living:

In the area of employment, rather than developing specialised workshops for people with disabilities, individual inclusion in regular workplaces can be facilitated by on-site and informal support from work colleagues. Fostering these types of supports also benefits the employment integration of other marginalised groups.⁵⁰

⁴⁴ Quinn, Quinn, Gerard: Disability and Human Rights: A new field in the United Nations, see *ibid* ad 35, p.267

⁴⁵ CESCR General Comment no. 5, see *ibid* ad 42, para 21

⁴⁶ *Ibid*, para 21

⁴⁷ Concluding observations – Tunisia, see *ibid* ad 8, para 33; Concluding observations – Spain, see *ibid* ad 9, para 45

⁴⁸ Concluding observations – Tunisia, see *ibid* ad 8, para 34

⁴⁹ Concluding observations – Spain, see *ibid* ad 9, para 46

⁵⁰ Hammarberg, see *ibid* ad 20, para 3.1.3.

Conclusion

Arising under the Article 27, perhaps the most interesting issue in view of persons with intellectual disabilities is their consistent confinement to forms of work known as segregated sheltered workshops. While sheltered work is explicitly mentioned in the Article 27, it is evident from the text of the article that it is strongly inclined towards employment of persons with disabilities in the open market, and stressing the self-employment and entrepreneurship options. Additionally, while the Committee has yet to elaborate on the issue of sheltered employment forms in particular in view of persons with certain types of disabilities, the existing body of opinion speaks to the fact that states should be actively scrutinizing all sheltered, segregated and therapeutic forms of work which are arranged for persons with particular types of disabilities. Opening the labour market and tailoring measures of reasonable accommodation for persons of all types of disabilities is an obligation for states under the Convention.

BOSNIA AND HERZEGOVINA

Bosnia and Herzegovina (B&H) is administratively divided into two entities:

- Federation of Bosnia and Herzegovina (FB&H), and
- Republic of Srpska (RS).

This division includes the Brcko District, which is a special administrative unit over which the institutions of B&H exercise its sovereignty. The Constitution of Bosnia and Herzegovina is the highest legal and political document of this country. The entities are responsible for primary segments of the social structures that implement the policy of the country for persons with disabilities, and the state of B&H has been mandated only in some central areas of the economy and social development.

The B&H Constitution

The Constitution of Bosnia and Herzegovina defines that B&H and both entities shall ensure the highest level of internationally recognized human rights and fundamental freedoms. The Human Rights Commission for Bosnia and Herzegovina has been established for this purpose.¹ The rights and freedoms set forth in the European Convention for the Protection of Human Rights and Fundamental Freedoms and its Protocols shall apply directly in B&H. These documents shall have priority over all other laws.² All persons within the territory of B&H shall enjoy human rights and freedoms, which include: the right to life, the right not to be subjected to torture or to inhuman or degrading treatment or punishment, the right not to be held in slavery or servitude, or forced or compulsory labour, the right to personal liberty and security, the right to a fair hearing in civil and criminal matters, and other rights in connection with criminal proceedings, the right to private and family life, home and correspondence, freedom of thought, conscience and religion, freedom of expression, freedom of peaceful gathering and freedom of association with others, the right to marry and to found a family, the right to property, the right to education and the right to freedom of movement and residence.³ Non-discrimination relates to the enjoyment of rights and freedoms provided for in this article or in international agreements, which is ensured for all persons in B&H without discrimination on any basis, such as sex, race, colour, language, religion, political or other stance, national or social origin, association with a national minority, property, birth or other status.⁴

The Constitution of the Federation of Bosnia and Herzegovina⁵ and the Constitution of the Republic of Srpska⁶ also guarantee the human rights and fundamental freedoms to all citizens.

The Constitution of the Federation of Bosnia and Herzegovina, through a division of powers between the federal and cantonal⁷ authorities, prescribed social and health policies as the jurisdiction of both levels,⁸ with the provision that powers may be carried out jointly or separately, or by the cantons and coordinated by the FB&H government. In regard to these competencies, the cantons and the federal authorities agree upon their powers⁹ on an ongoing basis. The FB&H government has the right to create policy and enact laws pertaining to each of these responsibilities, while the implementation of social welfare policy and establishment of social welfare services is in the jurisdiction of the cantonal governments.¹⁰

¹ Dayton Peace Agreement, Annex 4, 14th December 1995, Constitution of Bosnia and Herzegovina, Article II, paragraph 1.

² Ibid., Article II, paragraph 2.

³ Ibid., Article II, paragraph 3.

⁴ Ibid., Article II, paragraph 4.

⁵ Ibid., Article II.

⁶ Official Gazette RS, No. 6/92, 8/92, 15/92, 19/92, 21/92, 28/94, 8/96, 13/96, 15/96, 16/96, 21/96, 21/02, 30/02, 31/03, 98/03, Constitution of Republica Srpska, Article II.

⁷ Cantons of Federation B&H represent administrative entity subunits of Federation B&H.

⁸ Official Gazette FB&H, No. 1/94, 13/97, 16/02, 22/02, 52/02, 60/02, 18/03, 63/03, Constitution of Federation of Bosnia and Herzegovina, Article III.2.

⁹ Ibid., Article III.3.

¹⁰ Ibid., Article III.4.

Strategies and National Disability Plans

The Strategy for Equal Opportunities for Persons with Disabilities in the Federation of Bosnia and Herzegovina 2011-2015, which was adopted in 2011, defines the objectives, measures, activities, deadlines and holders of activities in 12 areas that are of interest to people with disabilities, such as: social protection, affordable community living and housing, health care, education, sport and recreation, vocational rehabilitation and employment, family, information, communication, awareness, participation in public, cultural and political life, research and development, organizations for people with disabilities and international cooperation. Also, in 2010, the Strategy to Improve the Social Status of Persons with Disabilities in the Republic of Srpska was adopted for the period 2010-2015, which is based on providing equal opportunities in life and meeting the specific needs of persons with disabilities. The Ministry Assembly¹¹ adopted in 2003 the Standard Rules for Equalization of Opportunities for Persons with Disabilities. After that, in 2008 the Policy related to disability in B&H was adopted and it ratified twelve articles of the European social charter. In 2009 the Ministry Assembly in B&H signed and ratified the UN Convention on the Rights of Persons with Disabilities. With the adoption of these documents B&H bound itself to a new approach regarding disability which is based on human rights and a social model, and on harmonization of the domestic legislation and practice with standards foreseen in these documents. With the aim of improving the social position of persons with disabilities in RS, local action plans regarding disability were adopted in Derventa and Doboju in 2009 and in Doboju at the beginning of 2010.

¹¹ The Ministry Assembly is the executive authority in Bosnia and Herzegovina which exercise its rights and duties as government functions, according to the Constitution of B&H, legislation and other regulations in Bosnia and Herzegovina

EQUAL RECOGNITION BEFORE THE LAW

Legal and Policy Analysis

In B&H, the laws of FB&H and RS should provide special protection to all persons who are unable to take care of themselves, their assets and their interests. The mechanisms of deprivation and limitation on legal capacity, as well as placing of such people under guardianship are in accordance with the constitutional arrangement of B&H, regulated by special laws of the RS and FB&H. In addition to the family laws and laws on non-contentious proceedings as the primary sources of law, there are a number of other regulations relating to specific issues of concern to them (e.g. the Law on Administrative Procedure, the Law of Obligations, Inheritance Law, the Law on Settling of Conflicts and Authority in Family and Inheritance Matters).¹² Adults who are deprived of their legal capacity due to specific, subsequent circumstances which have reduced or excluded the ability to participate in legal matters independently and, therefore, are placed under guardianship when it comes to their health, physical, mental and social ailments. Placing a person under guardianship first requires a court decision on deprivation of legal capacity. The guardianship authority appoints his or her guardian only after the court in a non-contentious proceeding has issued a decision that the adult is deprived of legal capacity.

According to the FB&H Law on Non-contentious Proceedings¹³ and the RS Law on Non-contentious Proceedings,¹⁴ the main reason for deprivation or restriction of legal capacity is the fact that an adult, because of his or her total or partial inability of reasoning, is unable to care for his or her own rights and interests. In FB&H, the procedure of deprivation and reinstatement of legal capacity is regulated by the FB&H Family Law, in addition to the FB&H Law on Non-contentious Proceedings.¹⁵ Specifically, the FB&H Family Law enumerates conditions for deprivation and limitation of legal capacity. It lists, as examples, the causes that can lead to deprivation and limitation of legal capacity of an adult, such as mental illness, “mental retardation”,¹⁶ excessive consumption of alcohol or narcotic drugs, dementia and other causes.¹⁷ However, the RS Family Law does not cite any reasons for deprivation or restriction of legal capacity. The above-mentioned articles of the FB&H particularly regulate the case of limitation of legal capacity for the same reasons as in the deprivation, with the provision that the condition is set that an adult represents a viable threat to his or her rights and interests or the rights and interests of others.

Procedures for Deprivation of Legal Capacity

The process of deprivation of legal capacity consists of two phases: the procedure for deprivation of legal capacity and the procedure for the placement of a person under guardianship. The procedure of deprivation and reinstatement of legal capacity may be initiated by the court on an *ex-officio* basis¹⁸ but it can also be brought forward by a certain persons. According to the FB&H Family Law, the procedure for deprivation of legal capacity may be initiated by: a guardian, the spouse of the person being deprived of legal capacity, his or her direct blood relatives, and in the lateral line to the second degree,¹⁹ while under the FB&H Law on Non-contentious Proceedings and the RS Law on Non-contentious Proceedings, the procedure for deprivation and return of legal capacity may also be initiated, in addition to the above-mentioned person, at the suggestion of the plaintiff and other persons if

¹² Ceranic, Dimitrije. 2007. Guardianship of persons deprived of legal capacity (legal regulations) in B&H. Faculty of Law, University of Istocno Sarajevo.

¹³ Official Gazette FB&H, No. 2/98, 39/04, 73/05, Law on Non-contentious Proceedings, Article 29.

¹⁴ Official Gazette RS, No. 36/09, Law on Non-contentious Proceedings, Article 28.

¹⁵ Official Gazette FB&H, No. 35/05, FB&H Family Law, Article 325-329.

¹⁶ Most legal terminology that refers to persons with disabilities, especially to persons with mental or intellectual disability is archaic and politically incorrect. In most cases, the authors replaced such language with non-stigmatizing terminology. In other cases, the authors placed outdated terminology in quotation marks.

¹⁷ FB&H Family Law, Article 192.

¹⁸ FB&H Family Law, Article 326, FB&H Law on Non-contentious Proceedings, Article 31, and RS Law on Non-contentious Proceedings, Article 30.

¹⁹ FB&H Family Law, Article 326, FB&H Law on Non-contentious Proceedings, Article 30, and RS Law on Non-contentious Proceedings, Article 29.

provided by law. Entity laws²⁰ on non-contentious proceedings provide that the person being deprived of or reinstated his or her legal capacity may initiate the procedure if he or she can understand the meaning and legal consequences of his or her proposal, while the FB&H Family Law provides such a possibility only if the procedure has been initiated to reinstate the legal capacity for that person. According to the entity laws on non-contentious proceedings, the grandfather, grandmother, brother, sister, grandchildren and other persons may initiate the procedure for deprivation and reinstatement of legal capacity only if they permanently live in the same household with the person proposed for deprivation or reinstatement of legal capacity, while the FB&H Family Law does not state that they must live in the same household to be able to initiate these procedures.

The court in the territory of which the person being deprived of or reinstate legal capacity has a permanent or temporary residence has the authority to decide regarding the deprivation and reinstatement of the legal capacity. According to the entity laws on non-contentious procedure, the competent court shall immediately notify the institution of proceedings to the land registry department of the court on the territory of which the intangible property of the person to be deprived of legal capacity, or whose legal capacity will be reinstated, are located, and to notify the office responsible for maintaining the registers in which the person who is deprived of or reinstated legal capacity is registered. The court shall schedule a hearing, to which it shall invite the proponent, guardian of the person being deprived of legal capacity, or his or her temporary representative and the guardianship authority, and the person who will be deprived of or reinstated legal capacity only if he or she is able, according to court assessment, to understand the significance and legal consequences of his or her participation in the proceedings.²¹ According to the FB&H Family Law, the court at which the proceedings have been initiated to deprive or limit the legal capacity of a person, shall immediately notify the competent authority who will, if necessary, appointed a temporary guardian for that person. Unlike the permanent guardian, a temporary guardian's powers are limited. The duty of a temporary guardian shall cease when a permanent guardian is appointed, or when the court decision that there is no basis for deprivation of legal capacity has become final.²² All laws allow the court, if the person who will be deprived of or reinstated legal capacity is located in a health facility, to hold a hearing at that facility. During the proceeding, the person against whom the proceeding is being held must be examined by a medical expert of the appropriate specialty who will provide an expert opinion on the mental state of the person and his or her ability of reasoning. The judge shall be present during the expert evaluation, except when expert evaluation is performed in a medical institution.²³

When the court decides that all the requirements for the deprivation or restriction of legal capacity have been met, such decision shall be delivered to the proponent, to the person who is being deprived of legal capacity, to his or her guardian and to the guardianship authority.²⁴ The deadline for filing an appeal shall be within three days following the receipt of the decision to be submitted by any party involved in the procedure.²⁵ The FB&H Family Law has a contradictory provision on the court's obligation to deliver the decision to the person being deprived of legal capacity: in Article 335, paragraph 2, it states that the court does not need to submit the decision to that person if he or she cannot understand the meaning and legal consequences of it, or if it would be detrimental to his or her health, while in Article 337, paragraph 2, it gives the possibility to the same person, regardless of his or her health condition, to appeal within three days following the receipt of the decision. The first-instance court shall submit the appeal in writing to the second-instance court, which shall decide on the appeal within three days following the receipt of the appeal, and according to Article 337 of the FB&H Family Code, this period is much longer - 15 days following the receipt of the appeal. The court shall deliver the final decision on deprivation of legal capacity to the competent authority for keeping registers for the purpose of entry into the birth registry and to the land registry court. The court shall submit the final decision on deprivation or restriction of legal capacity, without delay, to the competent

²⁰ FB&H Law on Non-contentious Proceedings and RS Law on Non-contentious Proceedings.

²¹ FB&H Law on Non-contentious Proceedings, Article 31, 32, 33 and 34, and RS Law on Non-contentious Proceedings, Article 30, 31, 32 and 33.

²² FB&H Family Law, Article 195.

²³ FB&H Family Law, Articles 330 and 331, FB&H Law on Non-contentious Proceedings, Articles 35 and 36, and RS Law on non-contentious proceedings, Articles 34 and 35.

²⁴ FB&H Family Law, Article 335.

²⁵ FB&H Family Law, Article 337, FB&H Law on Non-contentious Proceedings, Article 42, and RS Law on Non-contentious Proceedings, Article 4.

authority of guardianship which shall, within 30 days following the receipt of the court decision, put the person who is deprived of legal capacity under guardianship.²⁶

According to the FB&H Family Law, guardianship duties are performed by the guardianship authority through an appointed guardian or indirectly through a professional.²⁷ A person whose personal characteristics and abilities respond to perform duties of a guardian, and who agrees to be a guardian, may be appointed a guardian. When appointing a guardian, the guardianship authority will take into account the opinion of the persons if he or she is able to understand what it is about, and the opinion of close relatives of the persons.²⁸ The same person may be appointed guardian for several residents, unless it is contrary to their interests.²⁹ A guardian shall conscientiously take care of the personality, rights, obligations and interests of residents and manage his or her assets, while appreciating the opinion of the resident who is able to understand what this means.³⁰ Also, the guardian shall file to the guardianship authority a report on his or her work and on the state of the resident's property in January of each year for the previous year, as well as when requested by the guardianship authority.³¹

The FB&H Family Law states that a person with limited legal capacity may, on his own, enter into legal transactions through which he or she acquires rights, unless otherwise specified by law. He or she may enter legal affairs which include handling of assets or assume liabilities only with the consent of a guardian. Also, this person cannot independently make statements concerning personal status, unless this law or a decision of the guardianship authority defines otherwise.³²

Guardianship over persons deprived of or with restricted legal capacity shall be terminated when a court decision is reached in a court proceeding by restoring their legal capacity. The court shall immediately forward the final decision on reinstating legal capacity to the guardianship authority.³³ In such case, the guardianship authority shall immediately issue a decision on termination of guardianship and discharge the guardian of his or her duties. The guardian shall submit a report on his or her work and the income situation of the person concerned at the time of termination of the guardianship. The guardianship shall also end upon the natural death of the resident, since in such event the subject of rights will have passed away. Declaring a person dead is equal to legal death.³⁴

Analysis of Practice

Besides the Cantonal Centre for Social Work (CSW) in Canton Sarajevo there are also nine municipal centres for social work. Official figures on the number of persons deprived of legal capacity and put under guardianship does not exist at the state level. However, based on data obtained from the Public Institution (PI) Cantonal Centre for Social Work in Canton Sarajevo, in the last few years there has been a steady increase in the number of persons deprived of legal capacity. This situation is clearly visible in Graph 1.

²⁶ Ceranic, Dimitrije. 2007. Guardianship of persons deprived of legal capacity (legal regulations) in B&H. Faculty of Law, University of Istocno Sarajevo.

²⁷ FB&H Family Law, Article 163.

²⁸ Ibid., Article 165.

²⁹ Ibid., Article 166.

³⁰ Ibid., Article 171.

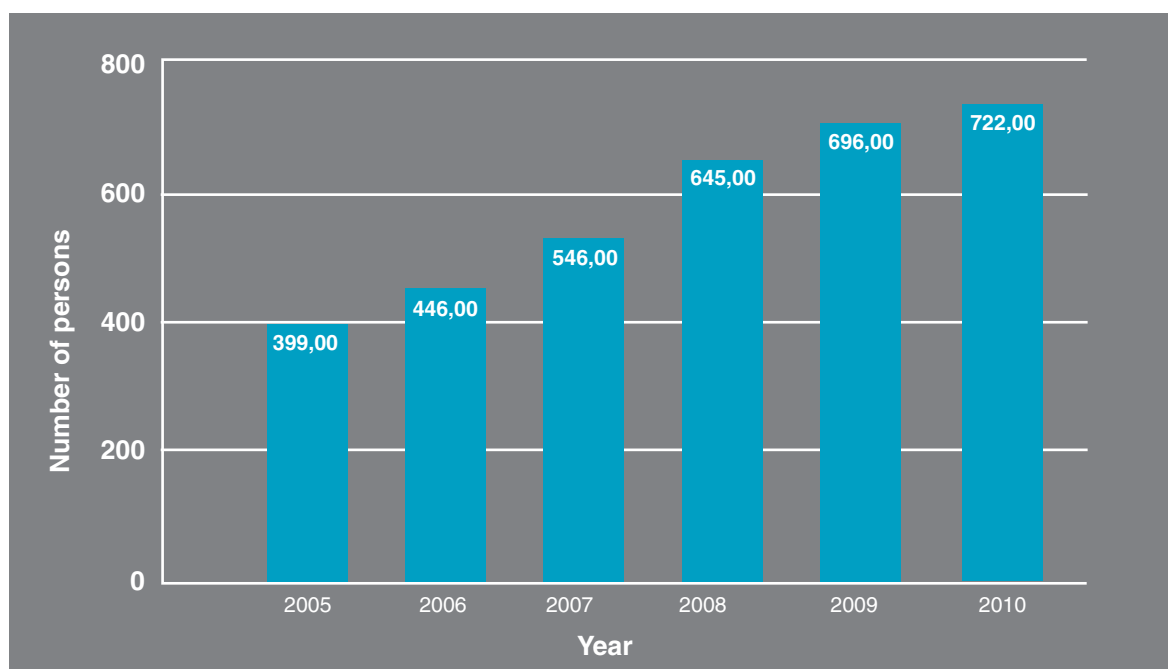
³¹ Ibid., Article 180.

³² Ibid., Article 194.

³³ Ibid., Article 196.

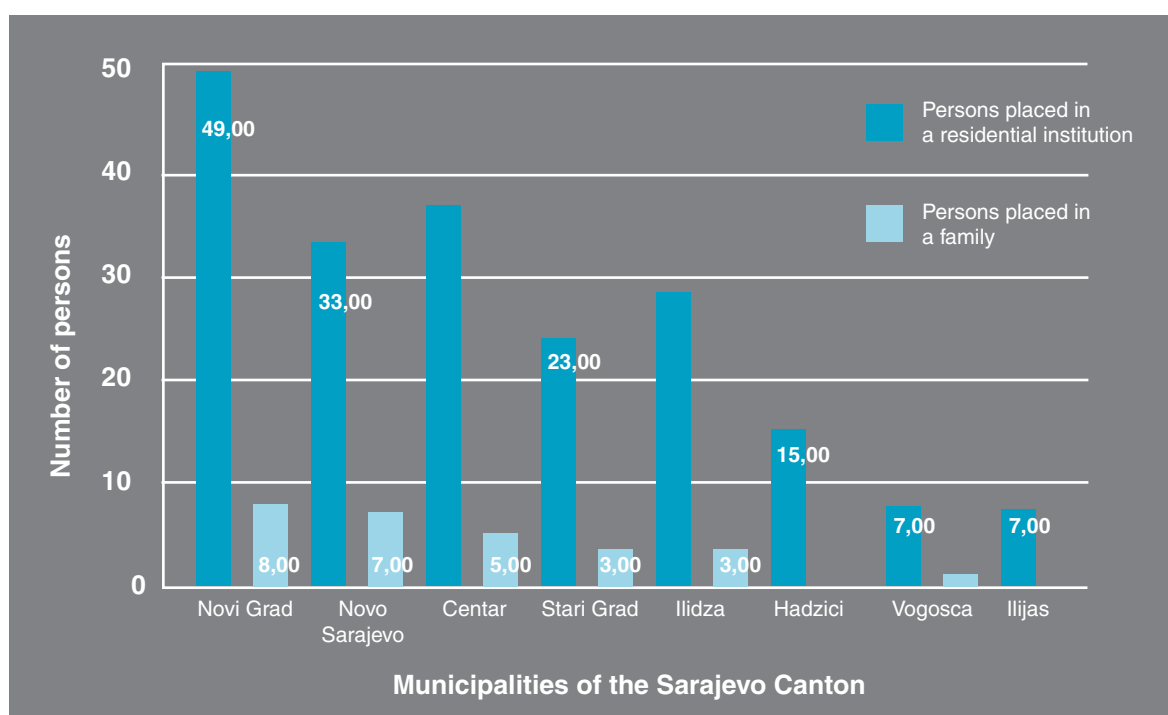
³⁴ Ceranic, Dimitrije. 2007. Guardianship of persons deprived of legal capacity (legal regulations) in B&H. Faculty of Law, University of Istocno Sarajevo.

Graph 1 – The number of persons for which the decision on deprivation of legal capacity has been made the Sarajevo Canton in 2005-2010



As the Graph 1 shows, from 2005 to 2010, the number of people deprived of legal capacity in the Sarajevo Canton annually increased by about one hundred persons. There are multiple explanations for this tendency. According to the experience of the PI Cantonal Centre for Social Work the most important reason for increasing the number of persons deprived of legal capacity is the passing of the Law on Protection of Persons with Mental Disorders³⁵ in 2001. Specifically, with the entry of this law into force, for all persons who were placed in social protection institutions, it was necessary to

Graph 2 – The number of persons under guardianship by Municipalities of the Sarajevo Canton and forms of protection in 2009



³⁵ Official Gazette FB&H, No: 37/01, Law on Protection of Persons with Mental Disorders.

initiate procedures for deprivation of legal capacity in order to provide consent for their further stay in these institutions by a legal guardian, or by persons accommodated if they were not deprived of legal capacity. Therefore, we can assume that the consequences of applying this law in practice are visible exactly in the increasing number of people placed in social protection institutions, deprived of legal capacity and assigned a guardian. Graph 2 gives an overview of the number of persons deprived of legal capacity and placed under guardianship obtained by PI Cantonal Centre for Social Work in Sarajevo in 2009.

As Graph 2 shows, there is a significantly higher number of people from the eight municipalities of the Canton Sarajevo who were housed in social protection institutions and had a guardian (guardians are employees in Centres for Social Work) in 2009 than the number of people who lived in their families and had a guardian. This trend may exactly have been the consequence of applying the Law on Protection of Persons with Mental Disorders.

Data about the number of residents accommodated in 5 social protection institutions in FB&H in 2011 who were partially or fully deprived of legal capacity and the number of residents who were not deprived of legal capacity are presented in Table 1.

Table 1 – Data on legal capacity for residents accommodated in five institutions in FB&H in 2011

Institution	Total number of residents	Number of residents not deprived of legal capacity	Number of residents who were partially deprived of legal capacity	Number of residents who were fully deprived of legal capacity
Bakovici	372	103	11	258
Nahorevo	257	172	2	83
Drin	519	37	2	481
Parazic	387	193	1	192
Duje	145	50	8	87
Total number of residents	1,680	555	24	1,101

According to the data from Table 1, in the institutions Drin (481), Bakovici (258), and Duje (87), there is a much greater number of residents completely deprived of legal capacity than the number of residents in institutions Drin (37), Bakovici (103) and Duje (50), who were not deprived of legal capacity. In the institution Nahorevo, the number of residents who were not deprived of legal capacity (172) is significantly higher than the number of those who were deprived (83), while in the institution Pazaric this number is approximately equal. In all institutions, there is a considerably smaller number of residents who are partially deprived of legal capacity. Although the delivered questionnaire seeking information explicitly requested that respondents should indicate the total number of placed residents with intellectual disabilities as well as the number of residents with intellectual disabilities who were not deprived of legal capacity, all the institutions filled in the data on the total number of residents accommodated, not limited only to residents with intellectual disabilities. Accordingly, we may assume that the institutions do not have the statistics on legal capacity by category of disability of residents accommodated. Thus, we may conclude that five institutions in FB&H, which took part in the survey,³⁶ accommodate a significantly higher number of residents who were completely deprived of legal capacity (1,101) than the number of residents who were not deprived (555).

According to the data obtained using the *Questionnaire for determining the condition of service quality in social protection institutions in the FB&H*, in these five institutes in the past year there were no cases of review of a decision on deprivation of legal capacity, reinstatement of legal capacity,

³⁶ For more information on the methodology, please refer to Annex X.

or cases where complete deprivation was replaced by partial deprivation. As far as cases in which partial deprivation was replaced by complete deprivation are concerned, in the past year, there was one such case in the CPI Home for Social Health Care for Persons with Disabilities and Other Persons - Nahorevo.

By deprivation of legal capacity and placement under guardianship, and also by placement of a number of those people in social protection institutions, people have been deprived, among other things, of the choice of housing, privacy, participation in public and political life, employment, management of their assets and the possibility of marriage. This is a direct violation of the principles of the UN Convention on the Rights of Persons with Disabilities (e.g. Article 12 Equality before the law, Article 19 Independent living and inclusion in the community, Article 22 Respect for privacy, Article 27 Work and employment, Article 29 Participation in political and public life).

Furthermore, the fact that social workers become guardians of a number of people further questions the efficiency and quality of the guardianship system in the country. For example, in 2009, the PI Cantonal Centre for Social Work in Sarajevo Canton employed 60 social workers, and each worker has been given guardianship on average of more than three people. The fact that the duties of a guardian assume care of the life and health of the person to whom he or she is a guardian raises the question of when and to what extent a social worker, in addition to regular duties at the Centre, can provide quality care to the person for whom he or she is ultimately responsible. Consequently, it is appropriate to ask why not to appoint for a guardian persons who have sufficient time and still meet all the requirements imposed by the FB&H Family Law, defining who may be appointed guardian. Unfortunately, even the closest relatives refuse to accept the duties of guardians, and social workers accept that obligation because the guardianship authority has no choice.³⁷

Mechanisms to protect the interests of persons who are under guardianship are not efficient, due to a lack of detailed regulations to specify the procedures based on which the rights of residents would be protected from abuse of power by a guardian, and due to the fact that the social work centres are not equipped with adequate human and material resources to effectively assess the behaviour and actions of each guardian.³⁸ To improve the guardianship system, among other things, it is necessary to meet the preconditions for full implementation of Article 181 of the FB&H Family Law, according to which a guardian has the right to remuneration and compensation for performing these duties. In this way the guardian would receive an incentive for better service provision and care, which would contribute to improvement of service users' life quality. However, the budget of the Sarajevo Canton does not provide for the preconditions for implementation of this article and the application of the ordinance on the amount and manner of payment of monthly fees for guardians. Until meeting all preconditions for the realization of this article, the PI Cantonal Centre for Social Work in Sarajevo will not have any option other than to appoint guardian social workers who are not objectively able to simultaneously perform their tasks and duties of a guardian.³⁹ As a result, not only will people be deprived of the ability to control their own lives, but they also will not be provided the option to have as their caregivers individuals who will continuously, with adequate monitoring, work to improve the quality of their lives and make decisions that are in the best interest of the person whose guardian they serve as.

Graph 3 gives an overview of persons who during 2011 lived in the local community in Bihac, Zenica, Mostar and Bugojno and who were or were not deprived of their legal capacity.

Data presented in Graph 3 shows that the situation regarding the deprivation of legal capacity is not different for persons with intellectual disabilities who live in the local community. According to information from persons who are members of Civil Society Organizations (CSO) in Bihac, Zenica, Mostar and Bugojno⁴⁰ in 2011 the number of persons deprived of their legal capacity (50) was significantly higher than the number of persons who were not deprived of their legal capacity (25). This can be

³⁷ According to the experience of the PI Cantonal Centre for Social Work in dealing with the procedures of incapacity and placement under the guardianship of persons with intellectual disabilities. Interview with Poturković Mirsada, Director of PI Cantonal Centre for Social Work.

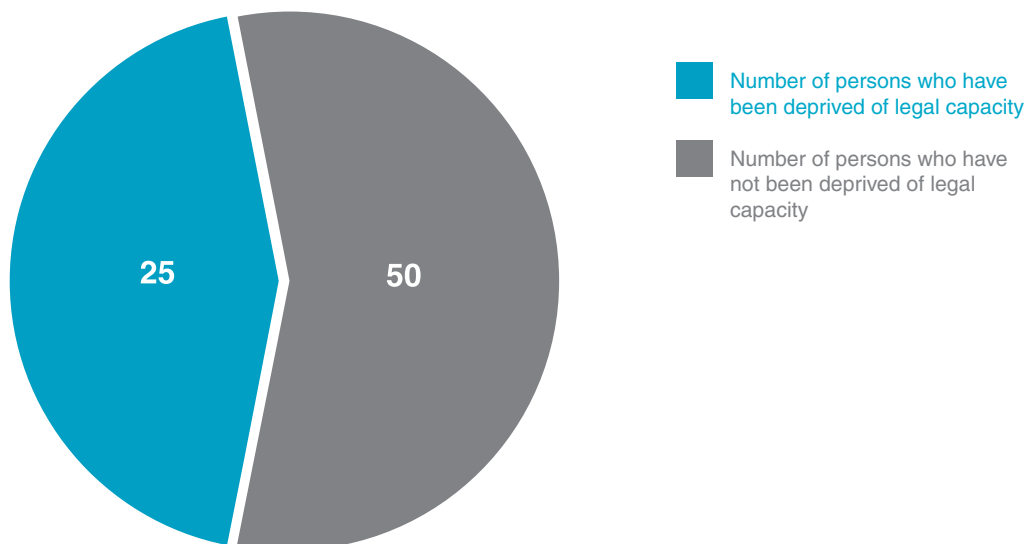
³⁸ Topic, Boris. Human rights of persons with mental disabilities: guardianship, and the limits of legal capacity. Accessed 28 November 2011. <http://arhiva.pulsdemokratije.net/index.php?&1=bs&id=713>.

³⁹ According to the experience of the PI Cantonal Centre for Social Work in dealing with the procedures of incapacity and placement under the guardianship of persons with intellectual disabilities.

⁴⁰ Not all members of CSO's were included in the research.

explained by the fact that for receiving some benefits it is necessary to deprive a person of his or her legal capacity.

Graph 3 – The number of persons who in 2011 live their local communities, and who have/ have not been deprived of legal capacity



Example of positive practice

According to information from the PI Cantonal Centre for Social Work in Sarajevo, before the war (pre-1992 period) there were positive examples of restoring the legal capacity to persons in Canton Sarajevo. However, in the period after the war there has been no official information about examples of reinstatement of previously deprived legal capacity.

Conclusion

Article 12 of the UN Convention on the Rights of Persons with Disabilities clearly states that all persons with disabilities shall enjoy full legal capacity on an equal basis with others in all areas of life. The Convention clearly says that such persons sometimes may require assistance in exercising their legal capacity, but this cannot be an excuse to deprive them of the right to make decisions independently.⁴¹ Accordingly, the UN Convention obliges the member states to take appropriate measures to provide these persons with access to the support they need to achieve their legal capacity. The Convention imposes obligations on states to ensure that all measures relating to the enjoyment of legal and business capacity provide for appropriate and effective safeguards to prevent abuse, in accordance with the provisions of international law regarding human rights.⁴²

These provisions of the Convention, in fact, oblige states to amend their laws which allow complete deprivation of legal capacity of adult persons with disabilities authorizing another person to make decisions on behalf of that person, and instead of such an approach to adopt legal regulations that will enable the said persons to exercise their rights through various forms of support in decision making.⁴³

If we take into account the consequences for the person placed under guardianship and information about the large number of persons residing in institutions who have been deprived of legal capacity,

⁴¹ Topic, Boris. Human rights of persons with mental disabilities: guardianship, and the limits of legal capacity. Accessed 28 November 2011. <http://arhiva.pulsdemokratije.net/index.php?&1=bs&id=713>.

⁴² United Nations Convention on the Rights of Persons with Disabilities, Article 12, paragraph 4.

⁴³ Topic, Boris. Human rights of persons with mental disabilities: guardianship, and the limits of legal capacity. Accessed 28 November 2011. <http://arhiva.pulsdemokratije.net/index.php?&1=bs&id=713>.

we can assume that these persons are exposed to violations of basic human rights. Perhaps the most important consequence of deprivation of legal capacity and putting persons under guardianship is that in this way they are prevented to decide where to live, with whom and under what conditions, and for them this is an obstacle preventing their ability to live in the local community. In such circumstances, people have no sense of control over their own lives, since they are deprived of the option to make decisions independently.

Furthermore, when a person is deprived of his or her legal capacity, he or she is automatically deprived of the right to parenthood. According to the European Convention on the Protection of Human Rights and Fundamental Freedoms, this is not a good practice because, although a person may be legally incompetent, it does not mean that he or she is not capable of being a good parent, or at least staying in touch with his or her children.⁴⁴ The right to family, as one of the fundamental rights, should not be so degraded, as is the case in our practice. By analyzing the domestic legislation and practices in light of relevant international standards, we can conclude that it is necessary for B&H to reform the existing solutions and, above all, to abolish the automatic deprivation of adults of fundamental rights, such as the right to family life and marriage, the right to vote and the right of access to courts.

The laws require that a person being deprived of legal capacity must be examined by a psychiatrist, and that the court shall make its decision based on facts established at the hearing. However, it often happens that in practice the courts make decisions on partial or complete deprivation of legal capacity based on the findings of a single psychiatrist. Also, it happens that the person whose fate is decided on often is not present at the hearing, or not even informed about the initiated procedure, because legislation leaves the court a possibility not to invite a person to the hearing if the court finds that he or she is unable to understand the importance and legal consequences of his or her participation in the proceeding. In addition, the appeal against the decision on deprivation of legal capacity does not postpone its enforcement, which practically means that even a first-instance decision deprives the person being taken away legal capacity his or her right to participate in some of the most important activities in his or her life.⁴⁵

By analysing domestic legislation and practice within the relevant international norms we can conclude that it is necessary for B&H to carry out reforms of existing solutions and for the country first of all to stop the automatic deprivation of adult persons' important rights, such as the right to family life and marriage, the right to vote and the right to access courts. It can be concluded that people with mental health problems, who are totally deprived of legal capacity, face serious obstacles in equal enjoyment of human rights and freedoms. Therefore, the current solutions in this area need to be replaced by more flexible forms of support tailored to individual needs and based on the principles of individual self-determination, dignity and autonomy. From the foregoing, it is evident that the existing legislative and legal framework in this area in Bosnia and Herzegovina needs to be reformed, and all of the above points to the need for immediate harmonization of the laws governing the procedure for deprivation or reinstatement of legal capacity with the United Nations Convention on the Rights of Persons with Disabilities.

Recommendations

Specific directions and measures that need to be undertaken to bring about full implementation of Article 12 of the UN Convention on the Rights of Persons with Disabilities, and which refers to equal recognition of persons before the law:

- Mandatory reform of legislation that defines this area in B&H as a whole and its harmonization with the UN Convention on the Rights of Persons with Disabilities;
- Cancel the process of legal capacity deprivation;
- It is necessary to review all cases of deprivation of legal capacity procedures. The result of the review should be full or partial restoring of legal capacity in all cases in which expert testimony would have determined the need and merits of its restoration;
- Set up special departments for procedures of deprivation and reinstatement of legal capacity within courts, where experts will be engaged who lack conflicts of interests;

⁴⁴ Ibid.

⁴⁵ Ibid.

- Perform a comprehensive analysis of the Institute for Medical Expertise of Health Conditions in Sarajevo and establish a labour control mechanism for the institute which is authorized to assess health conditions of people;
- In terms of the mechanism of guardianship authority, it is necessary to introduce less restrictive alternatives that will provide persons with mental disabilities with help and support in making decisions without resorting to deprivation of the legal capacity of these people and endangering their independence and human dignity;
- Create a database about the number of persons with deprived legal capacity or reinstated legal capacity on the national level;
- Enable greater access to Civil Society Organizations in processes of legal capacity deprivation/ reinstatement and ensure support to CSO which defend the rights of persons with disabilities so that their functioning is more effective;
- Implement various forms of education for persons with disabilities, their families and officials from public institutions with the goal to improve information about rights of persons with disabilities;
- Ensure free of charge judicial support and counselling for persons with disabilities and their families (family advisory centre, resource centres, etc.).

LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

Legal and Policy Analysis

Legal Framework

The exercise of the rights of persons with disabilities and their accommodation in residential institutions in FB&H are regulated by the following laws:

- Law on Takeover of the Rights and Obligations by the Founders of Social Protection Institutions in FB&H, (Official Gazette FB&H, No. 31/08),
- Law on Principles of Social Protection, Protection of Civil War Victims and Protection of Families with Children, (Official Gazette FB&H, No. 36/99, 54/04; 39/06 and 14/09),
- Law on Health Care, (Official Gazette FB&H, No. 46/10),
- Law on Health Insurance, (Official Gazette FB&H, No. 30/97, 7/02 and 70/08), and
- Law on Protection of Persons with Mental Disorders, (Official Gazette FB&H, No. 37/01).

In the Republic of Srpska, the rights of persons with disabilities and their placement in residential institutions are regulated by the following laws:

- Law on Social Protection, (Official Gazette RS, No. 5/93),
- Law on Health Care, (Official Gazette RS, No. 106/09),
- Law on the Protection of Persons with Mental Disabilities, (Official Gazette RS, No. 97/04), and
- Law on the Civil Service System, (Official Gazette RS, No. 68/07).

The FB&H Parliament took over the rights and obligations of the founders of social protection institutions in FB&H, as follows: Residential Institution for People with Mental Disabilities in Fojnica, Residential Institution for People with Mental Disabilities Bakovici, Residential Institution for the Protection of Children and Youth in Pazaric, Residential Institution for Education of Male Children and Youth in Sarajevo, Residential Institution for Education of Female Children and Adolescents Ljubuski.⁴⁶ There are four institutions for taking care of persons with disabilities in RS: Home for Male Children and Youth with Development Difficulties in Prijedor, Institute for Protection of Female Children and Youth in Visegrad, Institute for Blind Persons and Persons with Poor Sight Buducnost in Derventa and Social-geriatric Centre Banja Luka, department in Dragocaj. Beside these specialized institutions there are other homes, like homes for children and homes for old people which take care of persons with disabilities.⁴⁷

Placement in a residential institution is decided upon by the Centre for Social Work in the territory in which the person resides, on the basis of an opinion of the expert team of the Centre, an executive decision by a court and competent authority of the guardian or on the basis of the findings and opinions of the expert commission on disability for work, or the findings and opinions of adequate health facilities. The Centre for Social Work, which placed the person in a residential institution, shall monitor his or her treatment in the institution, for the purpose of care, protection and treatment of that person's physical or mental health condition.⁴⁸ Admission of people shall be done in the manner stipulated by the regulations of the residential institution. The residential institution shall accommodate the person referred by the centre for social work, and may deny admission to the sent person in the event of full capacity, as well as if, with respect to its activity, it is not able to provide appropriate services for users.⁴⁹

⁴⁶ Official Gazette FB&H, No. 31/08, Law on Takeover of Rights and Obligations by the Founders of Social Protection Institutions in FB&H, Article 1.

⁴⁷ Cuk, Mira, Dobras, Zoran, Hopic, Danijel and Hopic, Jasmina. Evaluation of capacity of institutions and organizations which work in provision of aid to persons with disabilities. Collection of papers Research of situation in field of disability in B&H, 2008.

⁴⁸ Law on Takeover of Rights and Obligations by the Founders of Social Protection Institutions in FB&H, Article 42.

⁴⁹ Ibid., Article 43.

According to the RS Law on Social Protection,⁵⁰ a social protection institution provides care (housing, food, clothing, care, assistance and nursing), education, training for specific work activities and health care, while the FB&H Law on Principles of Social Protection, Protection of Civil War Victims and Protection of Families with Children does not clearly state what a residential institution should provide to the accommodated residents.

The FB&H Law on Principles of Social Protection, Protection of Civil War Victims and Protection of Families with Children⁵¹ states that placement in a social protection institution may be provided for children and adults who need constant care and assistance in fulfilling life needs, if they cannot obtain them in their own or another family, or otherwise. The RS Law on Social Protection more specifically states who is entitled to placement in a social protection institution: a child without parental care and a child whose development is hindered by family circumstances, a child “mentally retarded” in development with a moderate, severe and profound mental disability level, multiple hindered in the development, a child suffering from autism and a child with disabilities in physical development who has no conditions to remain in his or her family; children neglected in upbringing and education; pregnant women and single mothers with a child under nine months of age who needs temporary care, a “disabled adult” with physical and sensory impairments, a severely chronically ill person and a “mentally retarded” person, who is unable to live independently in the family; a pensioner and other elderly person who is not able to live in a family or household; a person found vagrant or for other reasons in need of temporary care and supervision.⁵²

The B&H legislation stipulates that the provider of support services shall be registered as a residential institution and shall be established for education, science, culture, physical culture, health, child protection, social protection, social security and other activities stipulated by law, and clearly defines that a residential institution may be established by a domestic or foreign individual or legal entity in all forms of ownership.⁵³

According to the experience of the Centre for Social Welfare of the Canton Sarajevo (CSW), requests for accommodation of users are sent to all residential institutions, until a particular institution receives him or her, and if not received, the user remains in his or her current environment.⁵⁴ Although the staff in CSWs are not sure if the user is placed in an appropriate institution, they use the logic that it is better to settle persons anywhere than to leave them on the streets.

A positive example of an organization that currently provides support services in the local community in B&H is the Union of Organizations to Support People with Intellectual Disabilities SUMERO, which started this kind of support, financially supported by foreign and domestic donors. SUMERO as a union of civil society organizations promotes human rights, advocacy and self-advocacy of persons with intellectual disabilities, with the goal of their social inclusion through development of quality support services in the local community. The Union SUMERO counts over 30 members, local organizations for support of persons with intellectual disabilities, day centres and institutions for accommodation of persons with intellectual disabilities in FB&H and District Brcko. Partner organizations are local organizations from RS who are implementing projects with SUMERO.

The FB&H Ministry of Labour and Social Policy has recognized and supported the kind of providing support in the local community as one of the solutions for the future of people with intellectual disabilities. The best indicator of a wish for cooperation with the aim to improve life quality of persons with disabilities was shown by the ministry by its granting of consent to SUMERO for establishing the social protection institution named Sumero Centre for Support for Persons with Disabilities in the Community. The ministry also joined the creation of a rulebook proposal about minimum standards regarding space, equipment, staff and service provision in institutions for social protection in FB&H. In addition to government representatives, CSWs, and representatives of civil society organizations, the representatives of the Union SUMERO are also involved in developing these standards.

⁵⁰ Ibid., Article 36.

⁵¹ Ibid., Article 41.

⁵² RS Law on Social Protection, Article 37.

⁵³ Official Gazette RB&H 6/92, Decree Law on Institutions of FB&H, Article 2.

⁵⁴ According to the experience of the PI Cantonal Centre for Social Work in dealing with the procedures of incapacity and placement under the guardianship of persons with intellectual disabilities. Interview with Poturkovi? Mirsada, Director of PI Cantonal Centre for Social Work.

The rulebook proposal about minimum standards regarding space, equipment, staff and service provision in institutions for social protection in FB&H, which is currently being drafted, will define for the first time supported living as a special way of accommodating up to five service users together with organized permanent, daily or occasional professional support and help with the goal of satisfying basic life needs, as well as social, working, cultural, leisure and other life needs of a service user. With the aim of ensuring that the process of deinstitutionalization in FB&H goes in the right direction, this rulebook will define conditions for development and establishment of housing units in the local community, which will ensure that in one street there cannot be more than three houses/housing units in which supported living is organized and in one building there cannot be more than two flats/housing units in which supported living is organized. This will ensure that mistakes from many European countries, where smaller institutions (buildings) have been built, bungalows that contribute to segregation of this population in one place, and wrong processes of deinstitutionalization will be avoided..

Furthermore, the development of quality standards for social services in FB&H is planned, which will improve the living conditions of the service users. Together with quality standards the mechanisms of supervision and control will form the basic quality assurance system which the ministry can develop in further application for licensing of new service providers and evaluation of existing governmental and nongovernmental profit-making service providers.

At the state level, there is no strategy that is directly related to deinstitutionalization, but there are different policies, strategies and recommendations that clearly indicate that persons with disabilities need to participate fully and equally in society and to improve the quality of their lives as they choose. At the FB&H level, there is no document that talks about deinstitutionalization, but there is a strategy⁵⁶ that clearly defines that affordable living in the community means the existence of conditions that enable people with disabilities to exercise the right to make choices and ensure the quality of their lives, which is also a prerequisite for their independent living. Furthermore, persons with disabilities have the right to be provided the opportunity to choose where and with whom to live, and not to live in the imposed conditions and ways of life.

As for RS, there is no document or strategy for deinstitutionalization, but one of the strategies⁵⁷ mentions that an organized form of housing is arranged only for individuals who have become disabled as a result of war.

Analysis of Practice

Traditional placing of residents in asylum-type residential institutions is still prevailing in B&H, although the abolition of traditional residential institutions is becoming a request of a series of UN declarations and enters the area of human rights and is a form of segregation and ghettoization which is not accepted in the modern world.⁵⁸ The traditional model of segregation in the treatment of people with intellectual disabilities, as well as underdevelopment and lack of coordination of existing professional support services impedes the protection of basic human rights and adversely affects all areas of life of these people. If they have no family or if no one wants to take care of them, they are placed in large prison-type institutions where their basic human rights are violated.

The basic data on the structure of residents placed in 5 social protection institutions in FB&H in 2011 is shown in Table 2.

⁵⁵ Standards created by work group established by Federal Ministry of Labour and Social Policy.

⁵⁶ Strategy for the Equalization of Opportunities for Persons with Disabilities in FB&H 2011-2015.

⁵⁷ Strategy of Improving the Social Status of Persons with Disabilities in the Republic of Srpska 2010 – 2015

⁵⁸ Ibralic, Fata. 2011. Project: Establishment of a mixed model of social services for people with intellectual disabilities in the FB&H. Training material

⁵⁹ Ibralic, Fata and Smajic, Melika. 2007. People with intellectual disabilities - A contextual approach. Tuzla: Denfas.

Table 2 – Structure of residents placed in five institutions in FB&H in 2011

Variable	Category	Number of residents	%
Gender	Female	848	44.1
	Male	1,078	55.1
Age	Children	78	4.1
	Adults	1,848	95.9
Total		1,926	100.0

During visits, 1,926 people were placed in social protection institutions in FB&H In 2011, of whom 848 (44.1%) females and 1,078 (55.9%) males, with 1848 (95.9%) adults and 78 (4.1%) children. No children have been placed only in the institutions Nahorevo and Bakovici.

Table 3 shows information about the number of residents accommodated in 2 institutions for social protection in RS according to data from the Special Report on the Conditions in Institutions for Accommodation of Mentally Disabled Persons in B&H from 2009.⁶⁰

Table 3 – Number of residents in 2009 in two institutions in RS

Institution	Age		Gendre		Total
	Adult residents	Minor residents	Men	Women	
Home for children and youth with developmental disorders Prijedor	181	30	211	/	211
Institution for protection of female children and youth Visegrad	130	20	/	150	150
Total	311	50	211	150	361

As is visible in Table 3, in RS in two institutions there are 361 accommodated residents, of whom 150 are women and 211 men, and of whom 311 are adults and 50 are minors.

Graph 4 gives an outline of the structure of residents placed in four social protection institutions in FB&H in 2011, by categories of intellectual disabilities.

Graph 4 – Structure of persons placed in residential institutions by categories of intellectual disabilities



⁶⁰ Special Report on the Situation of Human Rights in the Institutions for Accommodation of Mentally Disabled Persons, 2009. Ombudsman report.

As can be seen, in four social protection institutions in FB&H the number of people with more profound intellectual disabilities (295) is the largest, followed by the number of people with moderate (234) and mild intellectual disabilities (116), and the smallest is the number of people with severe intellectual disabilities (74). Besides these, the Centre Duje accommodates 145 residents with intellectual disabilities, and authorities do not have any data on the categories of intellectual disabilities. Therefore, in five institutions where the research has been carried out there are 864 residents with intellectual disabilities. In the five institutions where research was done, 952 residents have one or more psychosocial disabilities (schizophrenia, addictions, psycho-organic syndrome), and 859 have other conditions (combined disorders, chronic diseases, infectious diseases, etc.). Among residents with mental illnesses and other conditions, there is a large number of residents with intellectual disabilities, who therefore have a dual diagnosis. Also, the institution Pazaric states that all listed diagnoses are quite questionable, because in many cases they are outdated and inaccurate, and it is necessary to re-categorize all diagnoses in order to get more accurate data. We can assume that the situation is similar in other residential institutions.

Table 4 – Number of residents placed in five institutions in FB&H according to the length of their stay

Institution	Length of stay in an institution						
	Total number of people	Less than 6 months	From 6 months to 1 year	From 1 to 5 years	From 5 to 10 years	From 10 to 15 years	Over 15 years
Bakovici	287	10	16	99	87	79	83
Nahorevo	257	28	76	79	65	9	0
Drin	519	8	9	129	203	62	108
Pazaric	387*	7	21	148	144	99	312
Duje	389	35	22	273	59	0	0
Total	1,839	88	144	728	558	249	502

* The number of people listed by the length of stay is 731. It is assumed that they have included the data from a larger number than the number of residents currently placed.

Although the questionnaire asked to specify the number of residents with intellectual disabilities given the time spent in the institution on the day of completing the questionnaire, most respondents provided data only related to the total number of residents accommodated. Therefore, the maximum number of residents with intellectual and other disabilities who live in institutions from 1-5 years is 728, and the minimum number of people who live in institutions less than six months is 88. However, it should be noted that 520 residents have been residents for more than 15 years. These data indicate a tendency that when people go to an institution, they often remain there until the end of their lives. The information about the number of residents who left the five institutions for social protection in FB&H in 2010 and 2011, presented in Table 5, supports the data.

⁶¹ Institution Bakovici, Drin, Pazaric and Nahorevo.

Table 5 – Number of residents who have left the 5 institutions in FB&H in 2010 and 2011

Institution	Return to their biological family	Going to foster families	Adoption	Return to the local community	Going to an other institution	Death
Bakovici	1	0	0	0	4	13
Nahorevo	0	0	0	0	3	148
Drin	6	0	0	1	13	33
Pazaric	4	0	0	0	23	26
Duje	25	0	0	2	8	12
Total	36	0	0	3	51	232

Regarding the qualification structure of staff employed in social protection institutions in 2011, the overall situation in five institutions that participated in the survey shows the following:

- One special educator for about 241 people;
- One psychologist, pedagogue, or pedagogue/psychologist, for about 240 people;
- One social worker for about 84 people;
- One occupational therapist for about 64 people;
- One medical technician for about 15 people;
- One nurse for about 10 people;
- One cook for about 49 people;
- One washer for about 113 people;
- One hygienist for about 42 people;
- One host for about 138 people.

Thus, most staff are employed in workplaces as nurses, medical staff, hygienists and cooks, while the least staff are employed in workplaces as special educators, psychologists, pedagogues or pedagogues/psychologists. In the special report of the Ombudsman, one of the recommendations given by the B&H Ombudsman after visiting institutions for care of persons with mental disabilities in B&H in 2009 is to match the systematization of jobs with the needs of institutions of this kind, and to engage a larger number of experts of various profiles necessary to work with people with mental disabilities. Also, a recommendation was to hire more doctors, special educators and other professional staff with regard to a number of staff of this profile registered at employment offices. According to the data on employees, in 2011, no significant progress was made more in terms of hiring of persons with higher education (e.g., one special educator is for 241 people). However, the number of professional staff employed in institutions does not create any fundamental or time conditions for such work, because the focus is on supporting a large number of people, so it cannot target individual needs and desires of each person. However, it is important to point out that new European models of support insist on directing the resources and employing professionals in the local community with the goal of developing supported living that will ensure full respect of persons' rights unlike in institutional care. Therefore, it is important to point out that the efficiency of support does not only depend on a sufficient number of employed professionals, but on conditions where the service is being provided as well. Effective planning of support means a good knowledge of a person in order to follow his or her real views and experiences, and is oriented to creating support in a way that it increases the opportunities for self-advocacy and personal decision-making. In person-centred planning, the boundaries of professional relationships are crossed and better mutual relations established between persons provided with support and specialists.⁶² Segregating conditions of institutions do not provide positive environment factors, which are among the preconditions for quality support.

⁶² Ibralic, Fata. Characteristics of modern models of support aimed at improving the quality of life of persons with mental retardation.

Analysis of the Quality of Services in Social Protection Institutions in FB&H

In the analysis of living conditions in five social protection institutions in FB&H, special attention was given to segments that are listed in the special report of the Ombudsman in 2009, and their recommendations. Firstly, as already stated in their report, there is no real categorization of institutions in B&H, particularly at the level of users' intellectual disabilities. The structure of people in institutions at the time of the visit in 2009, and the data Union SUMERO collected in 2011, shows that all categories of users can be found in all institutions. Thus, to date, there is no systematic placement in institutions, but the placement is according to the principle of "free space". The delegation of the Ombudsman of B&H noted during the visit that the basic problem of the institutions is overcrowding, especially in the FB&H. Overcrowding is evident even today, as can be seen in Table 6.

Table 6 – Estimated number of residents and number of placed people in 2009 and 2011 in five institutions

Institution	Projected number of people for accommodation during construction and opening	Number of accommodated people on the date of ombudsman's visit (2009)	Number of accommodated people on the date of completing the questionnaire (2011)
Bakovici	*	375	372
Nahorevo	150	**	257
Drin	*	520	519
Pazaric	460	384	387
Duje	300	324	389

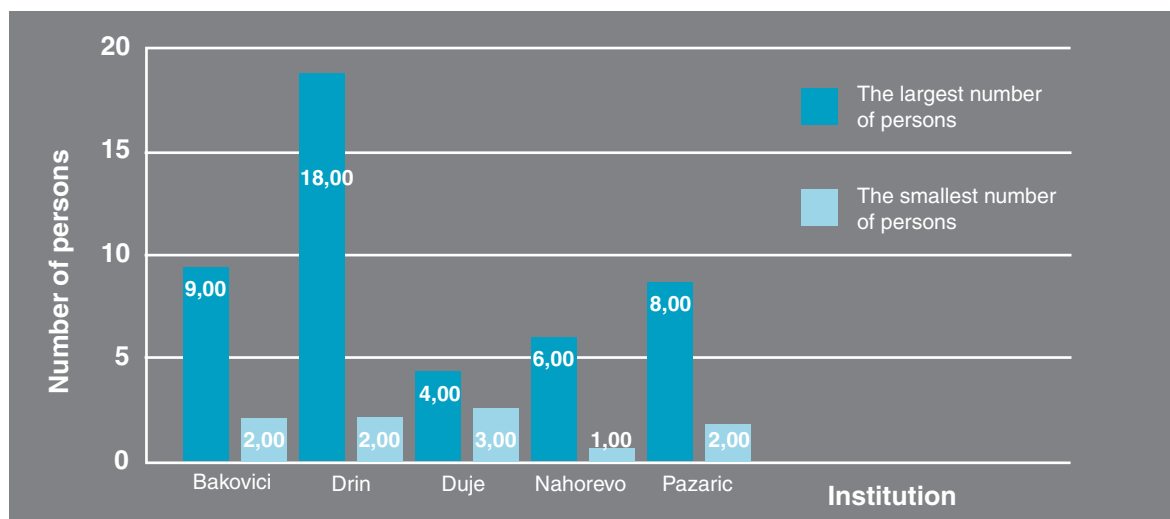
* Do not have the data

** The Ombudsman's Office has not visited the mentioned Institution

The analysis of the data on the number of residents placed in five of these institutions, shows that overcrowding is still evident, especially in the institutions Nahorevo (257) and Duje (389).

Right to Privacy of Residents in Institutions

The right to privacy of residents in institutions can be analyzed through different parameters. Some of them are existence of personal space and owning personal things. The Graph 5 gives an overview of the biggest and the smallest number of residents in a bedroom in the surveyed institutions.



The residential institution Drin states the largest number of residents placed in a bedroom (18), followed by the institution Bakovici (9) and Pazaric (8). In the institutions Drin, Bakovici and Pazaric, the smallest number of residents accommodated in a bedroom is two. Only the institution Nahorevo has bedrooms for one person, while at least three people are located in a single bedroom in the institution Dujë. Even the employees of the institution Pazaric state that 50% of bedrooms have a higher number of beds in relation to the prescribed number. It is interesting that they note a larger number of beds in relation to the regulated, but the data in Table 6 shows that their capacities are not booked. In the institution Bakovici, 30% of bedrooms have more beds than prescribed. In the institution Drin, there are also a larger number of beds in some bedrooms than the regulated. Bunk beds are available in the institutions Pazaric, Drin (bedrooms with nine bunk-beds) and Dujë. The institution Dujë states that they do not have more beds than the prescribed number. However, overcrowding of the institution indicates that there is a larger number of beds in the bedroom than prescribed.

The obtained data are in accordance with the 2009 Special Report of the Ombudsman, according to which the rooms where people were located, regardless of the size of the room, were full of beds, often placed on two floors, so it is not possible to talk about the standard of 4m² per person, which is required for rooms of people serving prison sentences. It can be concluded that people with intellectual disabilities in institutions have worse conditions than people in prison. These conditions of accommodation violate the privacy of residents and create conditions for a possible spread of infectious diseases, and it is difficult to maintain hygiene conditions at a satisfactory level. Overbooking of institutions favours the creation of conflict situations among users and prevents any kind of therapeutic work.⁶³

Table 7 presents information given about whether the residents own personal items in institutions or they share these items with other residents.

Table 7 – Possession of personal items in five institutions in 2011

Institution	Table	Night lamp	Nightstand	Chair and wardrobe	Own means for personal hygiene	Own key for the wardrobe	Possibility of locking the toilette
Bakovici	√ x	√ x	√ x	√ x	√ x	√ x	√ x
Nahorevo	x	x	√	√	√	√	x
Drin	x	x	x	x	x	√ x	√ x
Pazaric	√ x	x	√ x	√ x	√ x	√ x	√ x
Dujë	√ x	√ x	√ x	√ x	√	x	x

x every resident does not own √ every resident does own √ x some residents do own some do not

As far as owning personal things is concerned, not all residents placed in any institution have their own table and bedside lamp, while only in the institution Nahorevo all residents have a nightstand, chair and wardrobe. In some institutions, some residents have their own personal hygiene means (Pazaric and Bakovici), while in some institutions all residents have personal hygiene means (Dujë and Nahorevo), and in one institution (Drin) no residents own personal hygiene means. In the institution Nahorevo, people have the key to a locker for personal belongings, and it can be locked, while in the institution Dujë the lockers for personal belongings cannot be locked and residents do not have the keys to their closets. In the institutions Bakovici, Pazaric and Drin, some personal belongings can be locked and some residents have a key. The right to privacy is violated by the inability of people to lock the toilet facilities in the institutions Dujë and Nahorevo.

⁶³ Special Report on the Situation of Human Rights in the Institutions for Accommodation of Mentally Disabled Persons, 2009. Ombudsman report.

As far as the average number of people in living rooms is concerned, most of them are in collective accommodation in the institution Bakovici (30), then the institutions Pazaric (20), Drin (15), Duje (10-20) and Nahorevo (10), while the lowest average number of residents in the living rooms is in the dwelling units of the centre Buducnost - Bakovici (5). We assume that, in such circumstances, if a person decides to watch a show on TV, other people who are there at that time are forced to give in to his or her choice. Also, in all institutions, individuals are permitted to have intimate relationships, but there is no separate room for it, except in the institution Drin. Thus, the conditions for establishing intimate relationships have not been created.

Based on the above data, it can be assumed that non-possessing of personal belongings and personal space is partly the result of overcrowding of institutions, which usually receive more people than is allowed by their actual capacity and the Rulebook on general, technical and professional conditions for the establishment and operation of organizations of associated labour related to social protection.⁶⁴ Therefore, it is clear that in such living conditions, their right to privacy is violated. We can say that the right to privacy is associated with the right to individuality, and by neglecting the former, we deny the people the opportunity to develop as individuals and to develop their specific potentials thereby.

Health Care Service in Institutions

As far as the health care of residents in institutions is concerned, all institutions that participated in the study require medical examination and properly maintain health records for each person. Within the institutions Drin and Pazaric, daily examinations by general practitioners, dental, psychiatric, internist, laboratory, and gynaecological/urological examination and physiotherapy are available. In the institution Duje, examinations by general practitioners and physiotherapists are available daily, while a general practitioner comes to the institution Bakovici twice a week, and other specialists less frequently or as needed. In the institution Nahorevo, examinations by general practitioners, psychiatrists, internists and physical therapists are available weekly. The examinations that require tests not available in the institutions are performed out of the institutions. In all institutions, it is difficult to treat people whose place of residence is in other cantons. For example, an examination at a clinic and hospitalization of a person from the institution Pazaric, who is from some other canton, require the consent of the Health Insurance Fund from the place of residence. In the institution Nahorevo, people have no right to choose the method of treatment based on informed consent.

In the institution Pazaric, 10 people with intellectual disabilities developed problems related to mental health during their stay in the institution and began to use medical therapy, and in the institution Drin, 51 people with intellectual disabilities. Also, from a total of 85 people with intellectual disabilities placed in the institution Bakovici, 78 of them use drug therapy, but they state that residents already were receiving drug therapy upon their admission in the institution. The institution Duje did not specify the number of people with intellectual disabilities who have developed problems related to mental health, and the institution Nahorevo indicates that there are no records about the same. It can be assumed that segregation and inadequate living conditions (unfulfilled expectations, inadequate treatment by professionals, etc.) contribute to the development of problems related to mental health in institutions, as some people with intellectual disabilities did not have these problems before coming to the institution.

Restrictive Measures in Institutions and Treatment

In all institutions that participated in the survey, restrictive measures are performed in situations when a person threatens his or her own health or the health of others. Table 8 gives an overview of restrictive measures that are used in these institutions.

⁶⁴ Official Gazette of SR B&H, 1988. Rulebook on general, technical and professional conditions for the establishment and operation of organizations of associated labour in the field of social protection.

Table 8 – Restrictive measures used in five institutions in FB&H

Institution	Restrictive measure
Bakovici	<ul style="list-style-type: none"> • a written warning • prohibition of going out to the local community • prohibition of going to weekend - holiday • physical fixation
Nahorevo	<ul style="list-style-type: none"> • restricting independent leaving of the institution • medical therapy • admission to a particular clinic • physical fixation
Drin	<ul style="list-style-type: none"> • transfer to another department • in extreme situations, fixation
Pazaric	<ul style="list-style-type: none"> • physical fixation with special fixations (magnetic bandage) • medical therapy
Duje	<ul style="list-style-type: none"> • prohibition of going to the city the next 7 days • denial of privileges (using computers) • physical fixation

In all institutions, fixation of people is used as a restrictive measure, and medical therapy as a restrictive measure is used in the institutions Pazaric and Nahorevo. In the case of physical fixation, the institutions Pazaric, Bakovici and Nahorevo use fixation with bandages. Other restrictive measures mostly are prohibition of leaving the institution, denial of privileges and written warnings.

Although some institutions answering the question to specify the type of restrictive measures did not mention that they use medications, it is obvious that they actually use them as a restrictive measure because they referred to that as a way of dealing with situations of expressing aggressive behaviour. We conclude that physical fixation is used, based on existence of professional magnetic fixer, the specified time that residents usually spend in such a fixation and the number of residents subjected to these fixations. It is the same case with physical fixation, for which they state that they use it, regarding statements that there are professional magnetic fixations, the time that residents usually spend in such fixation, and the number of residents subjected to these fixations. Giving contradictory answers leads to a situation in which the staff and management of the institution might not understand the term restrictive measures and for what purpose they are used, or they may have intentionally avoided a direct and honest answer to this question if they do use fixation. Therefore, it is evident that the data obtained using a questionnaire should be complemented by the method of continuous and structured observation in order to get more credible information.

Employees of the institution Pazaric indicate that there is no room for isolation (as a restrictive measure). However, according to the 2009 Special Report of the Ombudsman, there was an isolation room, and during their visit the representatives of the B&H Office of Ombudsman for Human Rights for other purposes as well wanted to make sure that the facilities had enough daylight and inspected whether there was artificial light, beds and chairs. They also noted that the isolation sometimes lasted longer than eight hours (inspected books of records of isolation), although it usually lasted 1 to 2 hours. In 2010 and 2011, fixation with drugs/calming/ stunning of residents was used in 20 occasions, and physical fixation was performed in 20-30 procedures, with the longest time spent in physical fixation being two hours, and the shortest being 30 minutes.

In the institution Drin, there is no room for isolation as a restrictive measure. The longest time spent in physical fixation is two hours, and in 2010 and 2011, physical fixation was performed in 52 procedures, with the longest time spent in fixation lasting two hours and the shortest lasting 20 minutes. According to the 2009 Special Report of the Ombudsman, the employees said that the fixation and isolation were rarely used together with the use of medications.

In the institution Nahorevo, there is no room for isolation (as a restrictive measure). The longest time spent in physical fixation is during the night, and is a minimum of two hours. In 2010 and 2011, physical fixation was performed in 13 procedures.

In the institution Duje, there is no room for isolation (as a restrictive measure). Information on cases of physical fixation is not listed, and it is mentioned that the longest time spent in physical fixation is one hour. According to the 2009 Special Report of the Ombudsman, staff reported that medical therapy is used when a person is dangerous to himself or herself and the environment. Only in this institution, there are no records on the use of restrictive measures.

In the institution Bakovici, there is no room for isolation (as a restrictive measure), but as they mention, it exists, for medical reasons, and is used when a person endangers himself or herself or the environment. In this room, there is no protection against any possible injuries (the walls are not covered). According to the 2009 Special Report of the Ombudsman, the isolation room is equipped with two beds and natural and artificial lighting. In 2010 and 2011, physical fixation was conducted in seven procedures, and the longest time spent in it was two hours.

The recommendation of the B&H Ombudsman in 2009 was that the institutions should draw up standards for isolation and fixation based on the same principles for all institutions. A special procedure for the application of restrictive measures does not exist only in the institution Nahorevo. Specialized training of personnel to control aggressive and destructive behaviour does not exist in the institutions Nahorevo, Bakovici and Duje, and consequently, the question is how professional the employees are in the application of restrictive measures.

In the institution Pazaric, a person is only allowed to submit a verbal complaint regarding treatment, whereas in other institutions they can do it anonymously, using the complaint boxes. In addition, only in the institution Pazaric people are not informed about the possibilities and procedures for complaints. There is no form for complaints in any institution. Third-party support in the complaint process is not provided in the institutions Pazaric and Nahorevo. Only the institution Drin does not keep records of complaints. In the institution Drin, complaints are usually related to the very fact of stay in the institution, and they are all verbal. In the institution Bakovici, beneficiaries made only verbal complaints (not specified how many), and a third party made one complaint. Complaints are most often related to a lack of money. The institution Duje recorded one complaint of a beneficiary. It is interesting that there are also cases of abuse among people or by staff in the institutions, but the representatives of institutions did not state that there were any formal complaints in such cases. Table 9 gives an overview of the amount and types of abuse recorded among residents placed in an institution and abuse by staff.

Table 9 – Abuse in three institutions in FB&H in 2010 and 2011

Institution	Abuse among residents placed in an institution			Abuse by staff		
	Physical abuse	Verbal abuse	Sexual abuse	Physical abuse	Verbal abuse	Verbal abuse
Bakovici	13	6	0	0	0	0
Pazaric	50	100	0	0	0	0
Duje	22	122	0	2	0	0

In 2010 and 2011, in the institution Bakovici there were 13 registered cases of physical and six cases of verbal abuse between residents accommodated in this institution, in the institution Duje 22 cases of physical and 122 cases of verbal abuse, in the institution Pazaric 50 cases of physical and 100 cases of verbal abuse. As for abuse inflicted by the staff, only in the institution Duje have two cases of physical abuse from the staff been mentioned, but these reports also state that three procedures were started by the disciplinary commission. In institutions Nahorevo and Drin there are no records

of abuse cases, either from the staff or between residents. It is important to point out that we do not know if all the cases of abuse were reported and recorded, especially when we consider that in the institution Pazaric residents can make only verbal complaints. Also, we cannot ignore that in this case the perspective of residents has not been considered, but only recorded cases have been taken into account.

Education in Institutions

The institutions Pazaric, Nahorevo and Duje provide educational programs (which do not refer to regular education) for people placed in institutions, and the institution Bakovici only partially. Although the institution Drin has professional educators, educational programs are not provided. Although the institution Pazaric in the last year included 320 people in educational programs, it states that only 30 people were basically literate. The institution Duje has no records on how many people are literate and there are no special learning facilities. Also, educational programs in institutions are not often implemented by professional educators.

Although the collected data show that in some institutions educational programs are provided, we can say that the right to education in the institutions is neglected, because the institutions must ensure that the education of persons with disabilities is an integral part of the general school system.⁶⁵

In most institutions, there is no supervision in the work of staff. Although the recommendation of the Ombudsman was that all the institutions should draw up a plan and organize a system of continuous professional development programs for staff in institutions, not all institutions complied with this recommendation. Thus, in the institutions Bakovici and Pazaric there is no staff training program, while the institution Drin indicates that it exists partially (it is not clear what partially refers to). In the institutions Bakovici and Pazaric, all professional employees were trained to work with people with intellectual and other disabilities, while in the institutions Nahorevo, Drin and Duje they did not. The institution Bakovici points out that the institution itself provided all training.

All institutions organize meetings with people from other institutions (in the form of excursions, sports and other events). In addition, all institutions, except the institution Nahorevo, socialize with people from the local community (performances, concerts, tours, visits to local bars and restaurants). However, given the large number of residents in institutions, the fact that a large number of them do not leave the institution unaccompanied, and that a sufficient number of personnel who could be given to each individual are not employed, we can assume that a large number of them are not involved in interacting with people outside the institution.

Comparison of the situation in institutions shows that the institutions and life in them differ in some parameters, and, actually, if their activities were regulated legally, they should have the same standards. In addition, it is obvious that they often did not comply with the standards specified in the rules of general, technical and professional conditions for the establishment and operation of organizations of associated labour related to social protection,⁶⁶ or the recommendations of the Ombudsman from 2009. However, one of the Ombudsman's recommendations was to consider expanding the capacity of the institutions (especially the Drin). Thus, the institutions Duje, Drin and Pazaric are building additional facilities. However, this policy continues the practice of segregation and goes against the process of deinstitutionalization of persons with disabilities. Institutions should be encouraged to transform, rather than expanding physical capacity.

According to data which the Federal Ministry of Labour and Social Policy had at its disposal in 2011,

⁶⁵ According to Rule 6 (Education) of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, "countries need to acknowledge the principle of equal opportunities of education in primary and secondary schools, and colleges, for children, adolescents and adults with disabilities, in integrated conditions."

⁶⁶ Based on Article 136 Paragraph 2 Point 1 of the Law on Social Protection (Official Gazette of SR B&H, No 39/84) the President of the Republic Committee for Health Care brings the Rulebook on general, technical and professional conditions for the establishment and operation of organizations of associated labour in the field of social protection Official Gazette of SR B&H in 1988.

in nine cantons in FB&H⁶⁷ there is a total of 14,198 persons with intellectual disabilities. In Graph 6 there is an overview of persons according to their degree of intellectual disabilities.

Graph 6 – The number of persons by categories of intellectual disabilities in 9 cantons in FB&H

In Graph 6 it is visible that of the total number of persons with intellectual disabilities from nine



Cantons in FB&H persons with mild intellectual disabilities (5,495) and combined difficulties (4,867) have the largest number, followed by persons with moderate (1,840), severe (1,052) and profound intellectual disabilities (944). Therefore, it can be concluded that there are many more persons who need less support for community based living. In the Federation of B&H there are 944 persons with profound intellectual disabilities of whom 234 persons are residents in four institutions.⁶⁸ It is clear that with persistence of the parents, life of these persons with intellectual disabilities in their local community is possible. This information disproves all claims that institutions for accommodation of persons with severe and profound intellectual disabilities will always be needed, and that support services in local communities are necessary only for mild intellectual disabilities.

Community Based Services

The ultimate goal of the process of deinstitutionalization is to establish a system that provides opportunities, which is aimed at supporting people with disabilities in achieving and maintaining of optimum levels of independence and social participation, taking into account personal factors, environment and expectations. In such a system, a person has access to different services that provide him or her with opportunities and choice to decide about his or her own lifestyle. Equal access to everyday services and the services available at the community level (regular education, health, employment and social services) should be provided by individualized support services that suit individual needs, but also by referral to specialized services as needed.⁶⁹

In 1999, the Association for Social Inclusion of Persons with Mental Retardation of Tuzla Canton (TC), in the cooperation with the TC Ministry of Labour and Social Policy and the Centres for Social Work, started the process of prevention of institutionalization, and deinstitutionalization of persons with intellectual disabilities in Bosnia and Herzegovina. So far, 15 persons have been successfully taken into care in the local community, with the prevention of institutionalization of eight people and deinstitutionalization of seven people. Since 2011, SUMERO, in cooperation with the Association to Support People with Intellectual Disabilities in the Canton of Sarajevo, OAZA, and the Association of Parents and Friends of People with Special Needs Sunce from Mostar, has been trying to make positive changes through deinstitutionalization and prevention of institutionalization, and to enable people with intellectual disabilities to live in local community. It is a model that is currently supported

⁶⁷ FB&H consists of 10 Cantons. Federal Ministry does not have data from West-Herzegovina Canton, but they do have data from following Cantons: Una-Sana Canton, Posavina Canton, Tuzla Canton, Zenica-Doboj Canton, Bosnian-Podrinje Canton, Central Bosnia Canton, Herzegovina-Neretva Canton, Sarajevo Canton and Canton 10.

⁶⁸ Graph 4 on page 14.

⁶⁹ Axelsson, Charlotte, Granier, Pascal, and Adams, Lisa. Beyond deinstitutionalization: Unstable transition towards a system that provides opportunities in Southeast Europe, 2004.

by pilot projects, but it will be systematically supported by authorities after getting a work permit of the social protection institution at the level of the FB&H, SUMERO Centre for Support of Persons with Disabilities in the Community, which in January 2012 received a decision regarding registration. In 2011, SUMERO established the first residential communities in which the people with intellectual disabilities live. For now, four residential communities are established in Sarajevo (which prevented institutionalization of 11 people, and achieved deinstitutionalization of two residents) and one residential community in Mostar (which prevented institutionalization of three persons). Housing people with intellectual disabilities with the support of the community includes: living in dwellings in accordance with the preferences of individuals; supporting people in accordance with individual needs; assessment of skills for independent living for people and training regarding basic life functions; stimulation in their daily activities; encouraging the development of people's skills through active inclusion in community life; use of the planning model Person Centred Planning, which makes it possible to adapt the provided support to a person's individual needs and desires. The goal of Person Centred Planning is to determine every person's individual interests and needs and to structure the support based on those needs. The person is the active and key factor in the creation, implementation and evaluation of this support plan. The support plan defines the responsibilities of a person, the staff providing support, family and friends who care about the person, as well as the time frame in which the person in cooperation with all the mentioned persons should attain the appointed goals. Such approach helps the staff better to understand the needs of a person, to help her/him to set up balance between what makes her/him happy, healthy and secure, to maintain contacts with people from the local community that are important to him or her etc. Teams in five towns in FB&H (Sarajevo, Mostar, Bihać, Bugojno and Zenica) are trained and ready to provide this kind of services.

People with disabilities too often remain excluded from the primary health care service and are systematically oriented toward specialized medical institutions. However, the fact that in B&H there are 60 community-based rehabilitation centres established within the primary health care system in which people with disabilities can receive comprehensive medical services and rehabilitation care is a positive example. Between 1997 and 2004, in B&H 60 community-based rehabilitation services were established within the system of public primary health care. They are a success story of including rehabilitation care in primary health care, based on cooperation between different sectors of the community. Activities have been carried out related to the continuing education of employees in the rehabilitation service centres to enhance their clinical skills, development of policies that support rehabilitation services centres on the primary health care level, policy and management training designed for different actors working in sectors for disability and rehabilitation, as well as introducing the concept of mutual support between beneficiaries within the same group (peer support).⁷⁰ Today the services related to mental health in B&H are provided through a network of 63 centres for mental health (CMH), 38 in FB&H, 24 in RS and one in Brcko District.⁷¹

Personal Assistance Service in the Community

The service of personal assistance aims to support people with disabilities in their full participation within social flows of local communities and support in meeting basic life needs. However, systemic solutions in B&H do not anticipate providing personal assistance services, and therefore persons with disabilities are fully directed to the system of social protection, care and socialization within their families. Only civil society organizations provide a positive example of personal assistance. Thus, in B&H there are two organizations that provide personal assistance services. In the FB&H, the Union SUMERO, for the fourth year, is implementing the project Support for People with Severe Disabilities in Bosnia and Herzegovina, and one activity is related specifically to personal assistance. Currently, the project involves 14 people with disabilities who are provided with personal assistance services. In RS, although not legally defined, personal assistance service was recognized by the Banja Luka City Assembly and incorporated in 2007 into expanded social welfare services, and, together with the humanitarian organization Partner from Banja Luka, which trains and prepares personal assistants to work, has been successfully implemented for four years.

⁷⁰ Ibid.

⁷¹ Data obtained through a telephone conversation with the management of Center for Mental Health.

Institutions vs. Services in the Community

For the purpose of this publication, SUMERO sought data from the Organizations for Cooperation and Development at the Embassies in B&H regarding whether and how much they have invested in the reconstruction of institutions for residential accommodation. From the received data, it is clear that these organizations did not allocate any direct funds for institutions, but in several cases they donated some equipment, and they mainly funded the associations for support of persons with disabilities through small grants or project activities.

FB&H took over the rights and obligations of the founder of the social protection institutions in FB&H,⁷² but the institutions did not receive any funding from the FB&H as a founder.⁷³ According to data obtained from the FB&H Ministry of Labour and Social Policy, Cantonal Ministries of Health, Labour and Social Policy⁷⁴ did not invest any funds in the development and reconstruction of any institution in the FB&H, nor do they have planned budget funds for this purpose. These ministries through the CSWs only pay the accommodation costs for their beneficiaries in institutions. However, with the budget of FB&H in 2011 funds were granted for reconstruction of institutions for social protection in FB&H in the amount of 1,719,104 KM (0.9⁷⁵ million EUR). The funds are for institutions Bakovici, Drin, Pazaric and Institution for Education of Male Children and Youth in Sarajevo. The named funds are not completely paid to the institutions. It is concerning that some of these funds were spent on expansion of institutions' capacities, which is not in accordance with tendencies to transform institutions, and in future this and funds from other donors should be spent on establishing supported living in the local community.

According to the research SUMERO conducted, the institution Duje is funded from sources such as the Cantonal Ministries of Labour and Social Policy, private accommodation, personal participation of residents, donations (equipment, food, clothing, diapers), self-financing, the government of the Brcko District, and the centres of the social work. The institution Bakovici is financed by charging accounts for the service provided, from funds of state aid – founders, donations, and own funds, i.e. production. The institution Pazaric is financed from the budget, donations, and personal income earned by working of people who are placed in the institution. The institution Drin is funded from fees for services rendered (Centres for Social Work), from legacies (legacy, inheritance), donations and other sources in accordance with the laws. The institution Nahorevo is financed from the budget of the Canton Sarajevo and from its own revenues derived from provided accommodation services.

Therefore, the funding of activities of institutions is provided by fees for services performed, and a portion of the funds is provided through donations, humanitarian and other projects, and work on their own farm. Donations of food, clothing, bedding, hygienic supplies and other items are especially made by citizens during the religious holidays.

Table 10 - Total funds which the five institutions in FB&H receive regarding to number of residents

Institution	Accommodation price (average per resident)	Total number of residents in institution	Total amount of money (KM)
Bakovići	780 KM (400 EURO)	372	290,160 KM (148.500 EURO)
Nahorevo	from 273 to 670 (140 to 345 EURO)	257	121,175* KM (62,000* EURO)

⁷² Law on Takeover of Rights and Obligations by the Founder of Social Protection Institutions in FB&H.

⁷³ Special Report on the Situation of Human Rights in the Institutions for Accommodation of Mentally Disabled Persons, 2009. Ombudsman report.

⁷⁴ Ministry of Health, Labour and Social Welfare of the West-Herzegovina Canton, Ministry of Health and Social Policy of the Una-Sana Canton, Ministry of Labour, Social Policy and the Return of the Tuzla Canton, Ministry of Social Affairs, Health, Refugees and Displaced Persons, Ministry of Health and Social Policy of Central Bosnia Canton, Ministry of Health, Labour and Welfare of the Herzegovina-Neretva Canton and the Ministry of Labour, Social Policy, Displaced Persons and Refugees of Sarajevo Canton.

Institution	Accommodation price (average per resident)	Total number of residents in institution	Total amount of money (KM)
Drin	780 KM (400 EURO)	519	404,820 KM (207,000 EURO)
Pazarić	780 KM (400 EURO)	387	301.860 KM (154,500 EURO)
Duje	from 500 to 1,800 KM (255 to 920 EURO)	145	166,750* KM (85,500* EURO)
Total			1,284,765 KM (657,000 EURO)

*average amount of money

As is shown in Table 10, for accommodation of residents in institutions for social protection in 5 named institutions in FB&H, monthly allocated funds are approximately 1,284,765 KM (0.65 million EURO). Therefore, for accommodation of residents in institutions annually, 15,417,186 KM (7.8 million EURO) are allocated. This amount that is impossible to neglect through the transformation of the named institutions should be directed towards development of supported living in the local community.

Civil society organizations providing community services mostly find financing sources for their projects from the support of foreign and domestic organizations. Thus, viability of such services which are primarily provided to persons with disabilities through such projects is questionable from the financial point of view.

In general, investments of the government sector in the non-government sector in B&H in the last years have poured a large amount of funds in CSOs that provide services for social protection (even though this amount is lower than the amount for other types of CSOs)⁷⁶:

- Funds allocated for the NGO sector in B&H for 2007 were 107,219,316 KM (54.8 million EURO) while from that amount for disabled organizations 13,918,332 KM (7.1 million EURO) have been allocated.⁷⁷
- Funds allocated for the NGO sector in B&H for 2008 were 118,033,391 KM (60.3 million EURO), while from that amount 16,044,352 KM (8.2 million EURO) have been allocated for CSOs that provide different social services.⁷⁸
- Funds allocated for the NGO sector in B&H in 2010 were 114,078,183 KM (58.3 million EURO), while for CSOs focused on social services/social protection 24,277,062 KM (12.4 million EURO) were allocated⁷⁹

Evidence from the results of research and evaluation of alternatives to institutional care in the states of the European Union and Turkey support the transition to community-based services. A large number of studies have shown significantly better results when it comes to people who are provided support, their families, as well as staff providing support.⁸⁰ Comparison of institutional care for people with intellectual and other disabilities as opposed to supporting people in their local communities in the FB&H, also suggests the benefits of community based services.

Specifically, data on how much is the monthly cost of accommodation in the social protection institutions in FB&H in tested institutions is approximately KM 790 (approximately 400 EURO) (from 273

⁷⁵ All conversions to Euro currency depict approximate value, using the exchange rate at the time when this report was compiled.

⁷⁶ Except the year 2010.

⁷⁷ Allocations from the government sector for the non-government sector in B&H for 2007, Swiss Agency for Development and Cooperation – SDC, July 2008.

⁷⁸ Abdelbasit, Ana. 2009. 118 million steps to cooperation – allocations of the government sector for the non-government sector in B&H for 2008. Sarajevo.

⁷⁹ Muhic, A., Amina. 2011. Halfway there – allocations of the government sector for the non-government sector in B&H for 2010. Sarajevo.

⁸⁰ DECLOC report – Ad hoc expert group

KM to 1,800 KM (from 140 to 920 EURO). Data on the costs of people living in residential communities within the pilot program – Community Based Living with Support, implemented by the Union SUMERO - were continuously collected for each of the five housing units in Sarajevo and Mostar since their opening. In table 11 there is an overview of living cost for one person.

Table 11 - Price of living costs for one person who lives in a housing unit

Description of expenditure	Average amount
Housing costs	
House/apartment rent	110 KM (55 EURO)
Food	200 KM (102 EURO)
Utilities (water, electricity, heating, phone, garbage collection)	75 KM (38 EURO)
Insurance for person and flat	5 KM (3 EURO)
Clothing	50 KM (25 EURO)
Activities in the community (sports, cultural and leisure activities)	40 KM (20 EURO)
Staff	
Head of service, program coordinator, assistant in the housing unit, professional help and financial assistant	270 KM (138 EURO)
Total	750 KM (383 EURO)

In table 11 it is visible that life for one person in the local community for one month costs on average 750 KM (380 EURO). The named expenses refer to paying rent utility costs (water, electricity, heating, phone, garbage collection, management of the shared parts of the building), food, hygiene, clothes, shoes, insurance for flat and residents and unforeseen living costs (e.g. service of house appliances). Besides that this price also includes calculation of the expenses for the staff members who work with the person: program coordinator, assistant in the housing unit, professional support (psychologists, social worker, special teachers, and medical staff when needed) and a financial assistant. It is important to point out that for the establishment of housing units, depending on how well the housing unit is equipped, an average of 2,500 KM (1,280 EURO) is needed for equipping the apartment.

Thus, the life of people with intellectual disabilities in the community requires equal, if not less money. This result is consistent with other studies that show that there is no evidence that the community-based support models are more expensive than the institutional model. Also, the care in social protection institutions may be more expensive than the support provided in the local community.⁸¹ When comparing these costs, it is important to keep in mind the complexity of the relation between needs, costs and outcomes of both models of social services.

For example, funds allocated for accommodation of S.D. and A.D. in the institution Duje were monthly 1,200 KM (610 EURO), while for their life in the local community around 750 KM (380 EURO) is being allocated monthly, and at the same time the life quality has been improved. The most important difference between the support provided within the institutional model and the support in the community is that an assistant in a residential community has enough time and space to provide support tailored to individual needs of each person, which is not the case with staff in institutions due to their overbooking. Although the representatives from the institutions indicated in questionnaires that only certain people have individual plans, employees are not familiar with the new principles of support, such as Person Centred Planning, so people placed in institutions are deprived of such forms of support. By

⁸¹ Ward, H., Holmes, L. and Soper, J. 2008. Costs and Consequences of Placing Children in Care. London: Jessica Kingsley Publishers according to ad hoc expert group.

contrast, for all persons with intellectual disabilities living in residential communities individual plans and person-centred plans are created, which make it possible to adjust the level, scope and method of support to every person in accordance with his or her needs and in the way he or she wants it. In this way, the individuality of each person is supported and his or her lifestyle respected. Thus, people living in the community in this way take a more active role in managing their support, and thus they take control of their lives. The person is no longer just a service beneficiary, as is any person who is placed in a social protection institution, but he or she becomes an active member of the community and makes choices and decisions, participating in the creation of support that will be provided for him or her, respectively, becoming an active part of his or her community and making choices and decisions. For example, in most institutions they do not have a choice of daily meals or the possibility of cooking by themselves, which takes away their right to choose. On the other hand, in residential communities, all people learn to cook and choose the meals.

Involvement in the local community has an impact on quality of life. Given that the majority of social protection institutions are of half-open type, we can assume that most of the activities are carried out within the institution and not included in the local community. By contrast, people in residential communities are involved in many activities offered by the local community and use community services to an extent equal to that of any other citizen. It is important to point out that the activities in the community are organized with the support of local Union SUMERO members through different sports, cultural, educative contents which are funded through projects like e.g. activities of the social club.

The existing legal and financial frameworks are inadequate to support the development of comprehensive community services to meet the needs of people with intellectual disabilities. Although community services are essential to guarantee the fact that persons with disabilities will be able to enjoy their rights, they themselves are not sufficient. Services must promote community life, to be focused on enabling people with disabilities, including people with intellectual disabilities, to be included in their communities and to reach their full potential.⁸² A large number of civil society organisations in Bosnia-Herzegovina mainly organize labour and occupational workshops for people with intellectual disabilities. However, if the activities of these workshops do not involve other people from the local community, this, perhaps unwittingly, encourages the process of segregation. Because of the lack of funds and creativity of workshop coordinators, often persons who are included in those workshops are forced to choose what is offered and not what they want to do. Therefore, occupational workshops should more focus on activities in the local community by using resources in the local community.

The question that arises is to what extent people with intellectual and other disabilities who live in the community are in general aware of their rights and ways of exercising them. Often they are represented by others and do not have the opportunity to represent themselves. To this end, Union SUMERO employed a spokesperson for people with intellectual disabilities, who, as a person with intellectual disabilities, contributes to self-representation of this population and to promotion of their potentials. In this regard, a working group composed of volunteers, people with intellectual disabilities and a spokesperson has created an easy-to-read and understand UN Convention on the Rights of Persons with Disabilities.

Data from the study of social competence of people with intellectual disabilities in Bosnia and Herzegovina done by Ibralic F. (2002), on a sample of 80 persons of both sexes over 20 years of age, of whom 27 persons have been placed in institutions and 53 persons live in families, revealed a low level of general competence of persons with intellectual disabilities. The achieved level of competence is associated with the effectiveness of support that these people have had in their lifetime, because this area vitally depends on knowledge, ingenuity, effort and motivation of parents, brothers, sisters, pedagogical and professional workers, and care in the local community. People with intellectual disabilities are practically dependent in the simplest everyday activities that are not associated with age and mental status. The author concludes that these people have no family support which would enable the development of their skills in line with their abilities, because they did not engage in any rehabilitation programs and are most often socially isolated, surrounded by their immediate family.⁸³

⁸² Adams, Lisa. 2008. Right to live in a community: Exercise of this right for people with intellectual difficulties in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo.

⁸³ Ibralic, Fata, and Mlika, Smajic. 2007. People with intellectual disabilities: Contextual Approach.

Successful Deinstitutionalization

The beginning of social inclusion of people with intellectual disabilities in Bosnia and Herzegovina is related to the objectives and activities of the Association for Social Inclusion of Persons with Mental Retardation in the Tuzla Canton. In 1999, with the cooperation of the TC Ministry of Labour and Social Policy and Centres of Social Welfare, the Association started the process of prevention of institutionalization and deinstitutionalization of people with intellectual disabilities in Bosnia and Herzegovina. This project promotes an inclusive model for the treatment of people with intellectual disabilities on the principle of community-based rehabilitation, in order to spread it to other parts of Bosnia and Herzegovina and eventually gain support of state institutions, and become part of the system.

Life stories of deinstitutionalized persons to whom the best point to the potential of these people for life in the community with person-oriented support and the improved quality of their life. The first one to leave the residential institution O.N. describes his life:

“Life in Pazaric was nasty, you could not go anywhere out, if others would make mistakes, it would be my fault, because I had to take care of others as a guard day and night ... I often imagined that I had got out of here, had my house, got married ... I spent many years there, and then I was told that I might return to Tuzla. I am the first who left the home - an institution in B&H... I made many friends in Tuzla ... In Tuzla, I saw with my brother and sister, and I visited them and we visit mutually to this day. In the Day Care Centre for the self-advocacy, I have learned a lot about cleaning, cooking and, most importantly, that people should respect, appreciate each other. In Tuzla, I started go out in the city, the theatre... I am hard working, so it is easy to earn for myself and I am never broke, and I do not regret spending with friends, to borrow if someone needed, all in agreement with my wife. I met my wife in the Centre, she was my friend at first, we went out together, after the Centre I would escort her home, we would often go for a coffee in town. She told me about her life, she had a very hard life just like me. Love has developed from that camaraderie. We were involved for about six months and decided to marry. We had a wedding at the Hotel Bristol, all my friends at the Centre were at the wedding, my brother, too, and a lot of students as well as some friends from Pazaric. Prof. dr. Fata and Novalija, who took me out of Pazaric were our wedding sponsors. My father-in-law gave us an apartment to live in it, and he moved into his house. In the building where I live, we have very good relations with neighbours. My wife and I take care of two people who stay with us and we are paid for that. I clean the stairs in the building in which we live, and neighbours often invite me to something privately and pay me for that. I earn enough and I can even save something – just in case. My life in Tuzla is a lot better than before, even with my father and my mother it was no better. My marriage is great, I love my wife and I would let no one destroy it. And for the future, I wish good health the most, for me and my wife.”⁸⁴

Conclusion

In Bosnia and Herzegovina, most people with disabilities live segregated in institutions for permanent housing or are isolated in their homes due to lack of community-based services. The principle of “urgency”, which is mainly used in the placement of persons in institutions, has led to the fact that all categories of persons are placed in them. When it comes to professional staff, the problem is unplanned and unsystematic reception of staff, which, in their expertise, does not suit the needs of these institutions,⁸⁵ as well as the lack of their continuous improvement that could lead to transformation of institutions. It is evident that the main problems faced by the institution for the care of people with disabilities in the Federation of Bosnia and Herzegovina are overcrowding, and an insufficient number or lack of professional and other necessary personnel to adequately respond to the specific needs of the people placed in them. Under such conditions, it is impossible to effectively provide the necessary support to residents placed in institutions.

⁸⁴ Ibralic, Fata and Smajic, Melika. 2007. Self-advocacy of People with Mental Disability: We are persons in the first place.

⁸⁵ Zecevic, Amir. 2001. Legal regulation and status of institutions over which the rights and obligations have been taken by the founder by FB&H Parliament.

Even without the above facts, the existence of institutions is questionable in terms of basic human rights, such as the right to life in the family or close to the family, the right to an intimate relationship, the right to marriage and family, the right to choose the place of residence, etc. Therefore, it is necessary to start observing the position of people with disabilities in our society in light of the need to protect human rights.

While community living is not regulated by state laws, the current situation in terms of practice indicates that there is a need of people placed in social care institutions for professional support services in the local community, that there are local examples of positive practices in developing services within the project activities of CSOs in the natural environment in places of living, as well as examples of good practice in the close environment and the EU countries.⁸⁶ Although there are the CSOs initiatives that are directed towards the development of local community-based services, comprehensive strategies and policies that exceed the humanitarian approach to deinstitutionalization and strive to build a society that provides opportunities and which is based on rights are rarely set. Local actors who initiate these changes are struggling to create a local community-based service which will be sustainable,⁸⁷ including the Union SUMERO, which for this purpose has initiated the process of registering the Social Protection Institution at the level of the FB&H SUMERO Centre to Support People with Disabilities in the Community. It will provide support services in the community, taking into account the observance of quality standards of services tailored according to the UN Convention on the Rights of Persons with Disabilities, which are currently under development. To make local community based services sustainable, the government must support their development and ensure equal rights and treatment for all citizens. In this context, it is important to note that the supported housing for people with intellectual disabilities does not require additional funds, but the funds already set aside to accommodate these individuals in institutions should be redirected to those people and their families, so as to achieve social inclusion of people with intellectual disabilities and exercise their basic rights. Even more, analysis of costs and quality of life in institutions and community life indicates a higher quality of life with the support in the local community for these people, although cash costs are lower than in institutions. Such a model of support that encourages the development of basic life skills and promotes social competence and quality of life is strongly against social exclusion of persons through placing these people into asylum-type institutions.

People placed in the institutions adapt to the established schedule of daily activities,⁸⁸ while living in the community, led by principles of person centred planning, puts the emphasis on individualization and, not ignoring the person's difficulties, emphasizes discovery and realization of his or her potential. Professionals must adjust their work to an individual's views of his or her own quality of life, i.e. his or her unique needs, personal goals and individual lifestyles. Effective planning of professional support to people with intellectual disabilities involves different areas of life (health care, housing, family, social/ emotional relationships, education, work and leisure), within which equal attention is given to the objective requirements (living environment) and to subjective indicators of quality of life (satisfaction and value system of individuals).⁸⁹ For planning and implementation of such support, it is essential to form expert teams that would provide people with support in their local communities.

Recommendations

Specific directions and measures that need to be undertaken for the full implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities, and which refer to independent living and being included in the community:

- Harmonize laws and bylaws in B&H with international standards which regulate independent living and being included in the community, which will enable persons with disabilities to choose and create under which conditions, with whom and where they want to live;
- The governments of Cantons in FB&H need to establish coordination bodies within cantonal ministries that will together through cooperation and activities take an effective approach to creation of action plans for implementing the Strategy for Equalisation of Possibilities of Persons with Disabilities FB&H 2011-2015 and planned activities on the cantonal level;

⁸⁶ Ibralic, Fata. 2008. Establishment of a Social Model in Rehabilitation of People with Mental Disabilities in Bosnia and Herzegovina.

⁸⁷ Axelsson, Charlotte, Granier, Pascal, and Adams, Lisa. 2004. Beyond deinstitutionalisation: Unstable Transition towards a System which provides opportunities in South-East Europe.

⁸⁸ Ibralic, Fata and Smajic, Melika. 2007. People with Intellectual Disabilities: A Contextual Approach.

⁸⁹ Experience of Prof. Dr. Fata Ibralic in the process of deinstitutionalisation, 2011.

- Analysis of the current situation and available resources;
- Setting a general vision for the future, respectively creating a strategy for transformation from the institutional towards living with support in the local community;
- Creating action plans and structures for their implementation (transformation of institutions, deadlines for transformation of institutions, development of support services for living in the local community, creating structures for including all relevant stakeholders);
- Forming centres for transformation of institutions at entity ministries;
- Development of service quality standards and continuous monitoring of their implementation in practice;
- Pilot process of deinstitutionalization and prevention of institutionalization;
- Development of needed training (training for trainers, training for staff in institutions, training for service providers in the local community, centres for social work);
- Define types of support for resolving issues of persons with disabilities, including independent living and supported living;
- Raise awareness among persons with disabilities about what their rights are and how they can exercise those rights;
- Public advocacy campaign (public awareness raising about the rights and possibilities of persons for life in the local community).

EDUCATION

Legal and Policy Analysis

Legal Framework

Regarding the education, B&H is in a unique position, considering that there is no general ministry of education at the state level. The Federal Ministry of Education, Science, Culture and Sports has only the role of a coordinator between different regions and administrations. Each canton has its own ministry with full competency to organize the education system and implementation of the same in its own region.⁹⁰ All persons in the territory of Bosnia and Herzegovina enjoy human rights and freedoms, which include the right to education and non-discrimination and enjoyment of rights and freedoms.⁹¹

In B&H, the Framework Law on Pre-School Upbringing and Education stipulates that each child has an equal right to access and equal opportunities to participate in appropriate upbringing and education without discrimination on any basis and equal access and equal opportunities which mean a guarantee of equal conditions and opportunities for all, for beginning and continuation of further upbringing and education. Also, children with disabilities are included in pre-school institutions according to programs adapted to their individual needs. For each child, an individual program will be developed adapted to his or hers abilities and capabilities. During the year before the beginning of elementary school, pre-school upbringing and education is obligatory for all children of pre-school age.⁹²

In accordance with the framework Law on Primary and Secondary Education in B&H children and youth with disabilities gain education in regular schools and according to programs adapted to their individual needs. An individual program, adapted to their abilities and capabilities, will be made for each student, with obligatory determination of status by special educator, and speech and language pathological status. Children and youth with disabilities and difficulties in development can be partially or completely educated in special upbringing - educational institutions, in cases when it is impossible to provide appropriate education in regular schools.⁹³

Framework laws are adopted on the level of the whole country and how they will be implemented is up to the entity and cantonal ministries to decide. The Ministry for Education and Science in Canton Sarajevo within its jurisdiction adopted laws, harmonizing them completely with the framework laws adopted at state level (B&H) from this domain.

Latest Change of Laws

The last change of legislation, which was made by the responsible Cantonal Ministry in late 2011, refers to adopting the law on changes and additions to the law on primary upbringing and education of Canton Sarajevo, and with it issues about support in class are also regulated. According to the law the process of upbringing and education in inclusive classes is performed with an assistant for children with special needs in accordance with pedagogical standards and norms.⁹⁴ Bearing in mind the different needs of children, and obstacles while learning and participation which the students are facing in the process of education, a structured organization of the support system is needed in the process of education. Support to students during their education, can be realized in four ways: assistant in class, personal assistant, psychological and educational-rehabilitation support, and peer

⁹⁰ Educational Policy for Students at Risk and Students with Disabilities in South-East Europe.

⁹¹ Constitution of Bosnia and Herzegovina, Article 2.

⁹² Official Gazette B&H, No. 88/07, Framework Law on Pre-school Upbringing and Education, Article 6, 12 and 16.

⁹³ Official Gazette B&H, No. 18/03, Law on Primary and Secondary Education in B&H, Article 2, 4, 6 and 19.

⁹⁴ Ibid., Article 10.

support. An assistant in class is a person who provides support and help in realization of the curricular and extracurricular process in an educational institution, while cooperating with teachers/educators, all children/students (children with special educational needs), parents, educators-rehabilitators, pedagogical service and the management of the educational institution. A personal assistant is a person who helps ensure that students with physical and sensory difficulties can actively participate in the educational process, equally with other students. Educational-rehabilitation support is intended for empowerment of students in overcoming the educational program and successful participation in the educational process, and it consists of individual work of the educator-rehabilitator different profiles with the child, counselling parents/guardians and cooperation with other adults referred to the child. Peer support in inclusive divisions enables the development of competences among children and socialization, and it motivates, but also participates in realization of cooperative learning.⁹⁵

The institutions which educate students with disabilities have a right to special budget resources in order to cover the expenses of a special curriculum or to adapt the school environment to the physical needs of the students.⁹⁶

School Enrolment

Students with difficulties in development and with combined disabilities are enrolled in regular or special primary schools and/or centres based on the findings and opinions of an expert commission. The basic aim of the special education is to provide to all students the same opportunities to participate in and enjoy education and participation in society, in the manner based on the principle of the best interest of a child. Special education is held in regular high schools on the basis of an integrated education principle, which means that all students, including students with disabilities, have a right to be in the regular class, if appropriate conditions are met in this regard, with the previously given opinion of the relevant minister. High schools for students with special needs in education and institutions can organize their work within a school centre with legal entity attributes, with special pre-school institutions and special elementary schools.⁹⁸

The regulations related to education define competencies of the local level in the education sector differently. This mostly relates to organization of the educational process, maintenance of school facilities, participation in creation of a part of the curriculum important for local community, as well as financing of education. Although some municipalities have been given competencies of wider range, due to the lack of financial resources they are often not fulfilled.⁹⁹

International Documents and National Strategies for Education

As a signatory of several international agreements, B&H is obliged to guarantee the right to education to every child. These agreements include: the International Covenant on Economic, Social and Cultural Rights; the United Nations Convention on the Rights of the Child and the European Convention for the Protection of Human Rights and Fundamental Freedoms. Also, in 2011 the Ministry Assembly of B&H brought a decision on adopting the Action Plan for Children of Bosnia and Herzegovina (2011-2014) which includes general goals presented at the World Summit for Children, and specially determined recommendations of the committee for the rights of children and other committees of the UN. In a number of recommendations, special emphasis includes also education of all children, recommending that education should provide equal possibilities to children in accordance with their interest and abilities, which derives from generally accepted, universal values and democratic society, and own values of the system based on specifics of the ethnic groups and national minorities who live in B&H.¹⁰⁰

⁹⁵ Action plan for reduction of obstacles for learning and participation of children with special educational needs in inclusive educational process, Association Life With Down Syndrom, 2012.

⁹⁶ Law on Elementary Upbringing and Education of Canton Sarajevo, Article 2.

⁹⁷ Official Gazette, Canton Sarajevo, No. 31/11, Law on changes and additions of the Law on Primary Upbringing and Education in Canton Sarajevo, Article 20.

⁹⁸ Official Gazette Canton Sarajevo, No. 23/10, Law on High School Education of Canton Sarajevo, Article 76, 78 and 81.

⁹⁹ Strategic Directions of Education Development in Bosnia and Herzegovina with Implementation Plan, 2008–2015.

¹⁰⁰ Action plan for reduction of obstacles for learning and participation of children with special educational needs in inclusive educational process, Association Life With Down Syndrom, 2012.

The long-term goals of the Strategic Directions of Education Development in Bosnia and Herzegovina 2008-2015 are: all teachers to finish trainings related to individualization and education inclusion and enable permanent education of children and youth with developmental disabilities.

Analysis of Practice

Based on the data available to Ministry of Education and Science of Canton Sarajevo in 2011, the total number of children included in regular school education in 65 primary schools during school year 2009/10 was 40,173, of whom 735 (1.8%) were students with special needs. Table 11 shows the number of children with intellectual and combined difficulties based on the data from 65¹⁰¹ schools in Canton Sarajevo.

Table 12 – Number of children with intellectual disabilities and combined disabilities in 64 primary schools in Canton Sarajevo in school year 2009/10

Municipality	Number of children
Ilidža	58
Novi Grad	76
Hadžići	47
Stari Grad	8
Vogošća	14
Novo Sarajevo	48
Centar	34
Ilijaš	7
Total	292

As can be seen in Table 12, during the school year 2009/10, 292 children with intellectual and combined disabilities were included in regular primary school education in 54 schools in the area of Canton Sarajevo, while 10 schools had none of the children with intellectual disabilities. There are 74¹⁰² schools in Canton Sarajevo, which means that even the Cantonal Ministry of Education and Science has no data about inclusive education of students with intellectual disabilities in all schools. It is further mentioned in the Cantonal Ministry that children with combined disabilities have two or more disabilities, of which none may be intellectual disabilities, but in most case is. This is another indicator of lack of full and detailed data at the cantonal level.

Enrolment in Education

According to data from the association Life with Down Syndrome, in the school year 2010/11 in 13 preschool institutions where preschool education is organized 3,558 children have been enrolled, where in three institutions for special upbringing and education three educational groups of children in preschool age have been formed and in the same institutions there were 66 children enrolled. Analysis of data from the research carried out by SUMERO in 2011 shows that of 32 regular primary

¹⁰¹ The Ministry Education and Science of Canton Sarajevo had data for 64 schools

¹⁰² From that 61 regular primary school, four special schools, three music schools and six private primary schools.

schools in Canton Sarajevo that took part in the research, in eight schools there are currently no children with intellectual disabilities (which does not mean that there were not any previously either).¹⁰⁴ Data on the number of children with intellectual disabilities who are going to regular schools in Canton Sarajevo is presented in Table 13.

Table 13 – Number of children with intellectual disabilities in 24 regular primary schools in Canton Sarajevo in school year 2010/11

Municipality	Number of children
Ilidža	40
Novi Grad	26
Hadžići	9
Stari Grad	8
Vogošća	3
Novo Sarajevo	12
Centar	25
Ilijaš	5
Total	128

During school year 2010/11 128 students with intellectual disabilities were included in regular primary school education in 24 primary schools, where municipality Ilidža (40) had most of children with intellectual disabilities which were included in regular education.

According to data from the association Life with Down Syndrome¹⁰⁵ 57,492 students in the school year 2011/2012 in Canton Sarajevo are enrolled in primary and secondary educational institutions. The number of students with special educational needs that are included in regular educational institutions is 1,468 students, which shows the analysis of the number of children, which is obtained from preschool (PI Children of Sarajevo and two private preschool institutions), primary (67 general primary schools) and secondary educational institutions (34). Therefore, with regard to the total number of children which attend regular educational institutions in the school year 2011/2012, 2.4% are children with special educational needs.

In Canton Sarajevo there are four primary and three secondary special schools.¹⁰⁶ Data from the association Life with Down Syndrome¹⁰⁷ about the number of students in special primary and secondary schools where children with special needs are educated for the period from the school year 2007/08 until 2011/12 in Canton Sarajevo are presented in Table 14.

¹⁰³ Action plan for reduction of obstacles for learning and participation of children with special educational needs in inclusive educational process, Association Life With Down Syndrom, 2012.

¹⁰⁴ Representative of one primary school told orally that the school cannot take part in the research because they do not have written information about how many students with intellectual disabilities attend their classes.

¹⁰⁵ Action plan for reduction of obstacles for learning and participation of children with special educational needs an inclusive educational process, Association Life With Down Syndrom, 2012.

¹⁰⁶ Center for Hearing and Speech Rehabilitation (within the Center is a primary and secondary school), Center for Blind and Visually Impaired Children and Youth (within the Center is a primary and a secondary school), Institution for Education, Work Rehabilitation and Employment of Mentally Retarded Children, Children with Autism and Cerebral Palsy Vladimir Nator, Institution for Special Education and Upbringing of Children Mjedenica and School for Secondary and Vocational Education and Retraining.

¹⁰⁷ Action plan for reduction of obstacles for learning and participation of children with special educational needs in inclusive educational process, Association Life With Down Syndrom, 2012.

Table 14 - Number of students in special primary and secondary schools where children with special needs are educated for the period from the school year 2007/08 until 2011/12

School	Number of children				
	2007/08	2008/09	2009/10	2010/11	2011/12
Centre for hearing and speech rehabilitation – primary school	37	36	37	35	33
Centre for blind and partially sighted children and youth – primary school	51	50	39	53	39
Centre Vladimir Nazor	146	146	148	148	150
Institution for special education and upbringing of children Mjedenica	100	106	106	87	108
Centre for hearing and speech rehabilitation – secondary school	26	19	10	18	23
Centre for blind and partially sighted children and youth – secondary school	41	42	42	37	36
School for secondary vocational education and job training	85	73	72	72	81
Total number of students	486	472	454	450	470

In the Table 14 it is apparent that in the school year 2011/12 in the named educational institutions, there were 470 students enrolled. In relation to the total number of students in regular primary and secondary schools, 0.8% students are being educated in the named educational institutions.

Only a small number of children from special homes/institutions in the area of B&H are included in inclusive education in local schools, which is shown by data in Table 15.

Table 15 – Number of children from special homes/institutions included in inclusive education

Institution	Total number of children	Number of children with intellectual disabilities	Number of children with intellectual disabilities in inclusive education
Home for children and youth with difficulties in development in Prijedor	15	15	0
Home for children with difficulties in physical or psychological development <i>Marija naša nada</i>	96	57	3
PI Home for Children Mostar	45	25	2
PI Dom – <i>Porodica</i>	135	28	6
Home for Children <i>Duga</i>	18	0	0
Pazarić	19	19	0
Duje	23	8	0
Drin	36	16	0
Total	369	168	11

As is visible in Table 15, out of the total of 168 children with intellectual disabilities located in seven homes or institutions in B&H only 11 are included in inclusive education. As for the remaining 157 children, we may assume that they are included in special schools or that they are not included in any form of education. Thus, a large number of children are deprived of one of their fundamental rights, the right to education. In the children's home Duga in Kulen Vakuf there are no children with intellectual disabilities accommodated.

Out of 24 schools which are currently attended by children with intellectual disabilities in Canton Sarajevo, 21 have developed individual education programs. 16 schools have developed an individual education program for each student with intellectual disabilities, a large number of schools (14) have no personal assistants for such students, and in some schools individual students have them and others do not.

In most cases, individual plans are created by an expert team (pedagogue, psychologist or special educator) of the Centre Vladimir Nazor in Sarajevo, or in cooperation with teachers for each subject, and it is rarely done by expert staff of schools in cooperation with parents. In some schools teachers alone develop programs of an individualized approach for students which have not been categorized. Although the laws which deal with this problem in FB&H clearly define that competent institutions will participate in financing of inclusive education, so far this has not become viable due to a lack of financial assets. Of those schools in which all or individual students with intellectual disabilities have assistants, they are allocated through implementation of the projects organized by civil society organizations, and mainly the association Life with Down Syndrome and association Duga, and these projects are (1) development of the support system in education in primary schools of Canton Sarajevo and (2) development of the early support system for children with Down syndrome in the process of inclusive education and upbringing. Implementation of these projects was supported by Municipality Ilidža and the Ministry of Education and Science of Canton Sarajevo. Often nobody finances the inclusion process, and assets intended for regular education are spent.

Considering that they are encountering different populations of students, teachers face new professional challenges, and should have permanent support and continuous professional development, but training which they go through is described by them as sporadic and insufficient. Education has mainly been related to the inclusion problem for children with special needs in school, and development and realization of individually adjusted programs. Such education is mainly implemented by civil society organizations (especially association Duga, Life with Down Syndrome, and Centre Vladimir Nazor). Education which teaching staff have undergone lasted one day at minimum and ten days at maximum. All teachers think that they are ready to attend additional educational training sessions and workshops in order to acquire new knowledge on education of children with difficulties, but workshops are on similar topics, without new topics and without real practical guidelines for teaching work. There was not a single education for competences in work with students with intellectual disabilities for teaching staff from nine schools, and five of them have students with intellectual disabilities, and teaching staff from three schools only went through on education, and also have children with intellectual disabilities.

Creating changed curriculums and programs in higher education institutions is a significant part of the inclusion process. Curriculums and programs at teaching faculties/departments are not adjusted to modern changes and movements in the direction of inclusive education. In this regard the exception is the Pedagogical Faculty and the department for pedagogy at the Faculty of Philosophy in Sarajevo, which have included in their curriculums and programs educational subjects related inclusive education. Furthermore, the department for Biology at the Faculty of Science and Mathematics has elective courses which deal with inclusive classes and talented students. Other circumstance that makes it harder is that these educational subjects are elective courses and they are chosen only by students who want to, not all future teachers. One thing is also a problem in higher education is the fact that the creators of curriculums do not understand the importance of the pedagogical and psychological group of educational subjects for future teachers, so that they add more courses that is related to their profession, and not the classes/professional competences which to a future teacher would enable to do his or her job in inclusive education.¹⁰⁸

¹⁰⁸ Ibid.

Thus, the reform of high school education should include additional education on special needs and educational barriers which they set, as well as on manners to overcome them in education of future educators, teachers, teachers of specialized classes, but also all other professions which will work with them in inclusive schools and inclusive society (pedagogues, psychologists, social workers, doctors, special educators).¹⁰⁹

According to statements of teachers, they are mostly trying to apply an individualized approach in work with students with intellectual disabilities in their mastering of the curriculum, but, they believe that work with children with specific difficulties requires inclusion of different services. An obstacle is the lack of personal assistants and teaching instruments. Teachers are trying actively to include children with intellectual disabilities in entire educational process based on their abilities. They include students with intellectual disabilities in the educational process through preparation of assignments adjusted for them, and include other students to help them in completing such assignments, and they also use various teaching tools if such are available (i.e. computer work with simple drawing tools and text processing tools, use of various audio-visual didactic instruments, etc.).

N.P. has Down syndrome and she finished primary school Grbavica 1. After that, with exceptional support from her parents, teachers and the school director managed to be enrolled in the Secondary School for Environment and Wood Design, and she is currently in the second grade.

Conclusion

Bosnia and Herzegovina is in a unique position considering that there is no ministry for education at state level. Besides the framework laws on the state level, in RS education is regulated with two more laws and one rulebook about education and the education in FB&H is regulated with 19 more laws. Each canton in FB&H has its own ministry, which has full responsibility to organize in its region an educational system and its implementation. Therefore, education in B&H is regulated with a total of 23 laws and one rulebook, and as a result unequal educational conditions are being formed at the national level.

Although Canton Sarajevo has some positive examples of inclusion, the percentage of such children compared to the number of children who should be included in regular education, not only in Canton Sarajevo but in all of B&H, is still small. Until cantons themselves start to implement legally set regulations, like financing of inclusion (i.e. so that every child with intellectual disabilities is ensured a personal assistant at school), the opinion that children with special needs should attend special schools will prevail in B&H and inclusion will stay a “sole letter on the paper”.

Generally it may be said that the inclusion process is going slowly and that schools are insufficiently prepared (e.g. the teaching staff is not systematically and in quality manner educated to implement this process). Education of future primary school teachers is still performed in a traditional manner with relatively few practical exercises and introduction of new forms of teaching work. Although, some changes have been made (transition from two-year to four-year study) they are more in the form of formal training and not in an essential and quality manner. With this the professional improvement of teacher does not follow the need of new times and demands which a teacher at a modern primary school should fulfil. There is a need for virtually every teacher to go through a form of additional training for innovation in educational work (e.g. individualization in education, interactive learning and teaching, educational inclusion, cooperation with parents, development of democratic environment at schools).¹¹⁰ Educations are mainly organized by civil society organizations, which is one of confirmations that ministries at their levels should intensify enabling of teaching staff which should be more systematic and in accordance with their needs.

¹⁰⁹ Support for inclusive education in curriculum, Association Life with Down Syndrome, 2011.

¹¹⁰ Educational policy for risky students and students with difficulties in Southeastern Europe, 2007.

In order for inclusion to become a reality in B&H, changes at many levels are necessary: at the classroom level, school level, community level and state level. Important preconditions are work on building tolerance, positive attitude and elimination of prejudice against special needs in schools, but also in broad public opinion, as well as changes in the system of general and special education which should be reformed and prepared for needs of new practice.¹¹¹

Recommendations

Specific directions and measures that need to be undertaken for full implementation of Article 24 of the UN Convention on the Rights of Persons with Disabilities, and which refer to education are:

- Establish mechanisms for tracking the application of legislation regarding inclusion of children with disabilities in regular education;
- Transform special schools into resource centres for assistance in classes;
- Continuously track and provide support to a child from birth through connecting and networking of different institutions and resource centres (educational, social and health sector) at the local level through service departments;
- Enable education and psychosocial help to parents through establishment of counselling centres for parents, so that they can receive as early as possible adequate professional help for education and socialization of their children;
- Increase the number of professional mobile teams or employ permanently professionals who will provide support in the implementation of inclusion and who will concentrate on continuous assistance to educational staff by designing and implementing individual programs for work with children in cooperation with their parents;
- Empower professional mobile teams who will sooner or later after regular classes provide additional classes according to individual needs of a student;
- Develop a support system in classes through establishment and development of an assistance model for children and persons with disabilities (assistant in classes, personal assistant, educational-rehabilitation and peer support);
- Introduce monitoring for mandatory funding of inclusion with state and cantonal budget funds;
- Introduce regular and mandatory professional training of human resources responsible for the implementation of a quality inclusive educational process (staff in kindergarten, as well as educational staff, professional staff and management in primary and secondary schools), with special emphasis on acquisition of skills and practical guidelines, and regular monitoring of their implementation;
- Include, without discrimination, in the regular educational system children with disabilities who are currently placed in institutions for social protection;
- Mapping the needs of children and youth with disability and available resources, through creation of a database about children and youth with disabilities in inclusive education and the needed support to human and all other relevant human resources, and through analysis of qualitative and quantitative conditions in educational institutions;
- Develop partnership between CSOs through programs and projects which contribute to better quality inclusive education;
- Changing curriculums and programs at teaching faculties with the goal to develop competences of future teachers for work in inclusive classes (attached classes), as well as the harmonization of curriculums and programs in pedagogical institutions and primary schools with the goal of respecting the needs and potential of every child.

¹¹¹ Support for inclusive education: teaching assistant, Association Life with Down Syndrome, 2011.

WORK AND EMPLOYMENT

Legal and Policy Analysis

Legal Framework

The Constitution of the Federation of Bosnia and Herzegovina emphasizes that all persons have the freedom to work.¹¹² The Republic of Srpska Constitution, in the section on human rights and freedoms, clearly defines that everyone shall have the right and freedom to work, that everyone shall be free to choose their vocation and occupation, and all work places and duties shall be accessible to everyone under the same conditions. In addition, every employed person shall have the right to remuneration in accordance with law and collective agreements. Employed persons shall be entitled to limited working hours, daily and weekly rest and annual holiday and leave with pay, in accordance with law and collective agreements. Employed persons shall have the right to safety at work, in accordance with law. Young people, mothers and persons with disabilities shall be entitled to special protection at work.¹¹³ There are two laws in Bosnia and Herzegovina that regulate the employment of persons with disabilities: the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in FB&H and the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska.

According to the FB&H law, persons with disabilities include those who have physical, mental or sensory impairments, which as a consequence have permanently or temporarily, for at least 12 months, reduced their ability to work or to satisfy personal needs in everyday life. A person with a disability is a person whose disability - in comparison to persons without disabilities of the same or similar age, same or similar education, in the same or similar work conditions, in the same or similar jobs – has a permanently or temporarily, for at least 12 months, decreased ability to work and have employment on the labour market under general conditions and fewer opportunities for job security and advancement. A similar definition of disability is also present in the Republic of Srpska law, except that the category of persons with disabilities, in addition to those listed in the B&H Federation law, includes persons with intellectual difficulties.¹¹⁵ In that regard, the definition stated in the Republic of Srpska law is in accordance with the definition from the UN Convention on the Rights of Persons with Disabilities, while the definition from the B&H Federation is not. Neither the entity laws nor entity strategies specify the rights of persons with intellectual disabilities as a category of persons with disabilities in regard to employment.

The mentioned laws in both entities regulate quota employment, self-employment and employment through protected enterprises and protected forms of employment. The downside of these laws is reflected in the fact that it is not harmonized with other laws, so the bonuses and benefits prescribed by the law cannot be fully used in practice. The Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities is in accordance with other laws as far as the issue of tax exemption is concerned. In B&H, in addition to the B&H Federation Fund for Professional Rehabilitation and Employment of Persons with Disabilities and the Republic Srpska Fund for Professional Rehabilitation and Employment of Persons with Disabilities, there are no services to support employment of persons with disabilities. The existing situation caused exclusion of persons with disabilities from the labour market, resulting in a very high rate of unemployment among this group, which is the reason why persons with disabilities belong in the category of population at risk of extreme poverty, further increasing their social exclusion.¹¹⁶

¹¹² Constitution of the B&H Federation.

¹¹³ Constitution of the Republic of Srpska, Article 39 and 40.

¹¹⁴ Official Gazette FB&H, No. 09/10, Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 2.

¹¹⁵ Official Gazette RS, No. 98/04, Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, Article 2.

¹¹⁶ Official Gazette B&H, No. 76/08, Disability Policy.

Conditions for Employment of Persons with Disabilities

Persons with disabilities are employed and work on the labour market under general and special conditions. Persons with disabilities are employed on the open labour market under general conditions in state bodies, judicial bodies, local administration bodies, public services, institutions, bureaus, public companies and other legal entities not established for employment of persons with disabilities in accordance with the law. Persons with disabilities have advantages for employment in entities from this article within the public sector if, in addition to the general conditions, they fulfil the special conditions for a certain vacancy. Persons with disabilities are employed under special conditions in an institution or business entity established for employment of persons with disabilities. Employment under special conditions, in regard to this law, includes employment of persons with disabilities in organizations and self-employment (starting of one's own business, performing of independent trading and performing of agricultural trading as the only and main activity).¹¹⁷

In the Republic of Srpska, persons with a disability of at least 40%, persons with at least 70% of physical disability and persons with mild and moderate “mental retardation” have the right to employment under special conditions regulated by this law, while in the B&H Federation this right is given to persons with a disability of at least 60%, persons with at least 70% of physical disability, if such disability results with decreased work ability, as well as persons with mild and moderate “mental retardation”. Special conditions from this article include conditions that are adjusted to the psychophysical and other capabilities of persons with disabilities.¹¹⁸

Exercise of Rights and Non-discrimination Provisions

Concerning exercising of rights from the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in RS, discrimination on basis of gender and sexual orientation is prohibited,¹¹⁹ while the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation does not include anti-discrimination provisions at all. The UN Convention on the Rights of Persons with Disabilities more specifically defines the prohibition of discrimination on basis of disability in regard to all issues related to all forms of employment, while such prohibition is not defined in the entity laws of Bosnia and Herzegovina at all. Also, these laws do not state that persons with disabilities are entitled, on equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment and the redress of grievance. Pursuant to the B&H Federation law, professional rehabilitation includes measures and activities performed with the goal of training of persons with disabilities for a certain job, their employment, maintaining of employment, career advancement or change of profession.¹²⁰ Furthermore, the entity laws do not state that persons with disabilities can exercise their labour and trade union rights, and do not have any reference on the protection of persons at work from forced or compulsory labour.

The laws of both entities give the right to employment to persons with disabilities who have a certified remaining work ability and who are trained for work. If training for work is performed by additional qualification or re-qualification of persons with disabilities for their employment, such form of professional training can be realized by a person with a disability not older than 55 and who, having in mind the nature and type of remaining work ability, can be trained for work on an full-time adequate job, which is determined by an expert body for assessment of work ability in accordance with regulations on the pension and disability insurance.¹²¹

¹¹⁷ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 15.

¹¹⁸ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in RS, Article 11, and Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 15.

¹¹⁹ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, Article 4 and 5.

¹²⁰ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 9.

¹²¹ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 16, and Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, Article 12.

Quota System for Employment, Stimulations and Sanctions for Employers

In the B&H Federation, for employment of persons with disabilities under general conditions, entities are obliged to employ persons with disabilities in proportion with the total number of employees in that entity, meaning that by December 31, 2011, at least one person with a disability out of every 24 employees, up to by December 31, 2012, at least one person with a disability out of every 19 employees and by December 31, 2013, at least one person with a disability out of every 16 employees. Entities that fail to meet this obligation are due to, during the payment of salaries, on a monthly basis, calculate and pay to the Fund for Stimulation of Rehabilitation and Employment of Persons with Disabilities the amount of 25% of the average salary in the B&H Federation for every person with a disability that they were obliged to employ.¹²² Business entities and other legal entities established in accordance with the law that are not obliged to employ persons with disabilities may employ these persons on adequate positions in accordance with this law, and gain certain incentives and benefits on the basis of that. Legal entities are obliged to pay to the Fund a special amount of 0.5% of the paid monthly gross salary of all employees, except in cases when they employ persons with disabilities.¹²³ In the Republic of Srpska, employment under general conditions includes employment of persons with disabilities in state administration bodies, judicial bodies and other state bodies, local administration bodies, public services, institutions and funds, as well as companies in the ownership or majority ownership of the Republic of Srpska. The bodies and other persons are obliged to have at least one person with a disability employed in an adequate position of their choice out of every 16 employees by December 31, 2009. An employer that is subject to this obligation but fails to fulfil it is obliged, during the payment of salaries, on a monthly basis, to pay to the Fund for Stimulation of Rehabilitation and Employment of Persons with Disabilities the amount of 0.2% of the paid monthly gross salary of all employees.¹²⁴

The incentives determined by the employment contract for persons with disabilities in this law are one-time material allowances, funds for adjustment of a place of work and conditions of work, credit funds under favourable conditions intended for purchasing of machines, equipment, tools, accessories necessary for employment of persons with disabilities, business premises and funds for compensation of differences due to decreased work effects or for co-financing a part of the salary of an assistant (assistant in work) to a person with a disability during work.¹²⁵ The rights from this article may be exercised by all employers that employ persons with disabilities, including companies for employment of persons with disabilities and sheltered workshops.¹²⁶

As for sanctions, an employer that fails to pay the special contribution (employment under general conditions) and treats a person with a disability as opposed to these provisions (employment under general and special conditions) and fails to submit information about persons with disabilities (keeping of register on employed persons with disabilities) shall be fined an amount from 1,000 KM (510 EURO) to 15,000 KM (7,700 EURO). In addition, an employer that uses the funds for special purposes in an inadequate manner (sheltered workshops and institutions may receive assistance and gifts in money or material funds) and fails to keep these funds for special purposes on a separate account or fails to adopt or submit an annual report on the funds for special purposes shall be fined from 1,500 KM (770 EURO) to 15,000 KM (7,700 EURO). An employer shall also be fined if it fails to pay the unused funds for special purposes to the Fund.¹²⁷ In addition, the Republic of Srpska law calls for fines of 1,000 KM to 15,000 KM (7,700 EURO) on employers that fail to separate by gender the statistical data and information collected, registered and kept, fail to enable public overview of these statistical data or fail to contract 20% of their needs for products and production services in

¹²² Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 18.

¹²³ Ibid., Article 19.

¹²⁴ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, Article 16.

¹²⁵ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 54, and Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, Article 44.

¹²⁶ Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation, Article 54.

¹²⁷ Ibid., Article 67.

accordance with provisions of this law. A fine of 1,500 KM (770 EURO) to 17,000 KM (8,700 EURO) shall be imposed on an employer that uses the funds for special purposes inadequately, fails to keep them on a separate account, fails to adopt or submit an annual report on the funds for special purposes and fails to pay the unused funds for special purposes to the Fund.¹²⁸

The Role of Employment Bureaus

The public employment service in Bosnia and Herzegovina consists of a state-level institution (Agency for Labour and Employment of Bosnia and Herzegovina), one bureau in each entity (Employment Bureau of the B&H Federation and the Employment Bureau of the Republic of Srpska) and one in the Brcko District of Bosnia and Herzegovina. Pursuant to its competences, the Agency for Labour and Employment of Bosnia and Herzegovina is not authorized to undertake active measures of employment on the local labour market nor to plan and/or implement employment policies directed toward any population of citizens of Bosnia and Herzegovina. The Agency is authorized for mediation of employment of B&H citizens abroad and conclusion of certain inter-state agreements on employment and social insurance, while it only coordinates activities on the local market together with the entity Employment Bureaus and the Brcko District Employment Bureau.¹²⁹

National Employment Strategies

In the Strategy for Equalization of Opportunities for Persons with Disabilities in the B&H Federation 2011-2015, one of the key obligations is overcoming of discrimination on basis of disability in regard to all issues related to all forms of employment, including employment conditions and employment, protection of health and safety in the place of work, general conditions of work and advancement in work. The legal regulation should be harmonized with international standards, with full respect of the situation in Bosnia and Herzegovina. The objectives of this strategy are to enable integration of persons with disabilities in the open labour market through application of stimulation measures, providing employment to persons with severe disabilities under protected conditions, stimulation of constant additional education of persons with disabilities for easier employment, increasing the interest of persons with disabilities for employment and establishment of a network of institutions that will enable and facilitate obtaining and maintaining of jobs for persons with disabilities.

The objectives of the Strategy for Improvement of the Social Position of Persons with Disabilities in the Republic of Srpska 2011-2015 include the development of institutional capacities for performing of professional rehabilitation of persons with disabilities, improving flow of information to authorities on the entity and local level, employers, trade unions and citizens on the existence of the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities as well as the benefits and other stimulation measures provided by this law, creation of preconditions for establishment of companies for employment of persons with disabilities, development of an inclusive labour market and development of social entrepreneurship, as well as improvement of partnership and dialogue between the public, non-governmental and private sectors in the area of employment.

Analysis of Practice

Problems with the employment of qualified persons with intellectual disabilities lead toward social isolation within the family and lack of meaningful life activities. The daily routine comes down to fulfilling basic biological needs, without fulfilling the psychological and social ones, which often results in maladjusted behaviour. The system of rehabilitation of persons with intellectual disabilities cannot be considered successful if it fails to open realistic opportunities for employment to these persons.¹³⁰

Within the Active Policy of Employment, the Federal Employment Bureau, together with cantonal services, is implementing the program of stimulation of employment of persons with disabilities through co-financing of employment and self-employment of persons with disabilities and other categories

¹²⁸ Ibid., Article 58.

¹²⁹ According to the Agency for Labor and Employment of Bosnia and Herzegovina.

¹³⁰ Ibralic, Fata and Smajic, Melika. 2007. Persons with intellectual difficulties: contextual approach.

who are difficult to employ. This program does not distinguish as a separate group persons with physical and intellectual disabilities, but they all fall under the category of persons with disabilities, and therefore there are no precise data on the exact number of persons with intellectual disabilities as beneficiaries of this program. Table 16 gives a chronological review of the number of employed persons with disabilities from 2005 to 2011.

Table 16 – Number of employed persons with disabilities from 2005 to 2011 in the B&H Federation

Year	Number of employees
2005	207
2006/2007	255
2008	18
2009	90
2010	167
Total	737

From 2005 to 2010, programs for stimulation of employment of persons with disabilities resulted in the employment and self-employment of 737 persons in FB&H. The average amount of co-financing per person amounted to 8,400 KM (4,300 EURO). The Government of FB&H also participated in financing of these programs. The average age of beneficiaries of programs for co-financing or self-employment was 40, the average degree of disability was 70%, and on the average, they had been looking for a job for 3.4 years. It is interesting to emphasize that in all these years, except for 2010, persons from several cantons of FB&H were employed through this program, while in 2010 this program included all ten cantons of FB&H. Thus, the support provided in the employment of persons with disabilities through this program became recognized on a wider territory of FB&H.

There was noticeably a smaller number of employed persons in 2008. Namely, although the Work Program for 2008 had planned to realize programs of co-financing the employment of persons unemployed for a long time, young persons without work experience and special groups of unemployed persons, including persons with disabilities, they were not realized because, due to objective reasons, funds were redirected toward material and social security of unemployed persons, and especially payment of financial compensation to demobilized soldiers.¹³¹

The Republic of Srpska Employment Bureau is not implementing programs of employment of persons with disabilities because, according to the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities, the bodies of state administration, judiciary and companies who are in the ownership or majority ownership of RS are obliged to employ persons with disabilities in accordance with the determined ratio in comparison to the number of employed workers. In that regard, the Fund for Professional Rehabilitation and Employment of Persons with Disabilities was formed, with its headquarters in Prijedor. Since the Law came into effect, the ratio of persons with disabilities in comparison to the number of employed workers in the period 2007/2009 was in accordance with the Law, while in 2010 a total of 9,527 KM (4,900 EURO) was paid to the Fund's account, and for 2011 this amount was 5,150 KM (2,600 EURO).

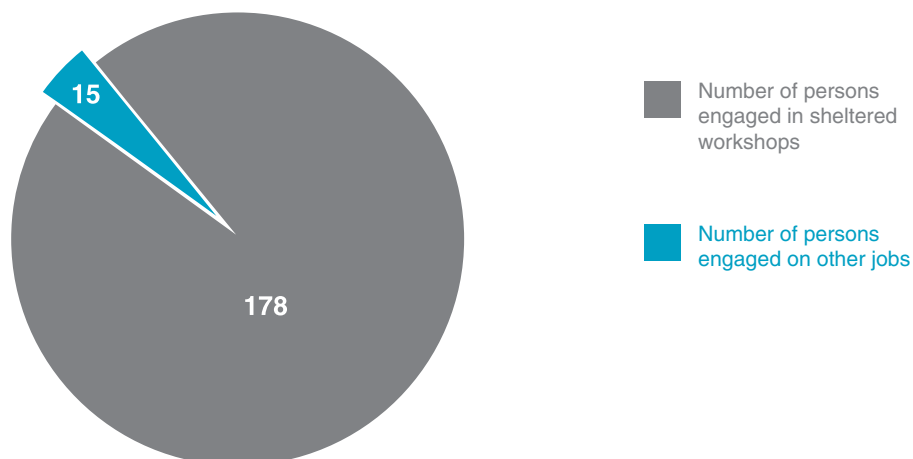
The Fund for Professional Rehabilitation and Employment of Persons with Disabilities in FB&H, based on first collected funds since the Fund was formed in 2011, brought the decision about distribution of 1 million KM (510,000 EURO), 850,000 KM (435,000 EURO) for programs and projects

¹³¹ Report on the Work of the B&H Federation Employment Bureau for 2008.

for conservation of the employment level in companies for employment of persons with disabilities, their development and improvement of professional rehabilitation, and 150,000 KM (77,000 EURO) for distribution of funds to employers for new employment of 30 persons with disabilities in a period for at least 12 months.¹³²

The data on the number of persons with intellectual disabilities employed in work-occupation workshops and other jobs in CSO are shown in Graph 7.

Graph 7 – The number of persons with intellectual disabilities in sheltered workshops and persons engaged for work on other jobs in 17 CSOs



Therefore, a significantly higher number of persons with intellectual disabilities are employed in work-occupation, meaning sheltered workshops (178), such as tailoring, weaving, art and candle-making workshops than on other jobs (15) such as waiters, assistant staff in kitchens, garden maintenance and couriers. In that process, persons working in sheltered workshops do not receive (five organizations) or occasionally receive (four organizations) financial remuneration depending on the number of sold products and donations, while in organizations where they receive financial reward (four organizations), the remuneration is rather low. These persons often receive other types of compensation, such as meal allowances, excursions, admission to cultural events, etc.

Employment of Residents Inside and Outside the Institutions

Residents accommodated in institutions for social protection in 2011 were rarely employed outside of those institutions, as delineated in Table 17.

Table 17 – Number of employed residents in institutions (work-occupational workshops or maintenance of the institution in 2011)

Institution	Residents employed in institution	Amount of fees for work in institutions	Residents employed outside the institutions
Bakovići	273	5-30 KM* (2,5-15 EURO*)	3
Nahorevo	101	5-10 KM** (2,5-5 EURO**)	0
Drin	170	10-80 KM (5-40 EURO)	0
Pazarić	146	5-150 KM (2,5-75 EURO)	0

¹³² Data obtained from www.fprzoi.ba.

Institution	Residents employed in institution	Amount of fees for work in institutions	Residents employed outside the institutions
Duje	27	20-100 KM (10-50 EURO)	0
Total	717	/	3

* 141 persons receive monthly payments in this range. One resident receives 200 KM (105 EURO) a month.

The remaining 131 residents do not receive any payment at all.

** Payments in this range occasionally receive five residents and only one resident receives 100 KM (50 EURO).

Therefore, 99 residents receive a payment in money.

In institutions for social protection in FB&H in work-occupational workshops or in jobs of maintenance of institutions there are 717 residents employed and accommodated, while only three residents are employed outside of the institution.

In the Drin institution, residents are mostly engaged in maintenance of collective sanitizing of interior premises, maintenance of outdoor premises and in assistance to the technical and door keeping services. For their engagement, 170 residents receive monthly financial remuneration in the range of 10 to 80 KM (5 to 40 EURO). The institution allocates 3,500 KM (1,800 EURO) monthly for these purposes. Other types of compensation include everyday supplying with coffee and cigarettes and occasional compensation in the form of birthday celebrations, trips to concerts, shows, etc.

In the Duje institution, residents are employed in laundry rooms, rooms for ironing of clothes, and as construction workers, waiters and nurses. A total of 27 residents receive monthly financial remuneration in an amount ranging from 20 to 100 KM (10 to 50 EURO). They also receive packages, sweets and gifts occasionally. This institution has the smallest number of work-occupied residents (27).

In the Pazarić institution, residents work mostly in ceramics, carpentry, art, weaving workshops, tapestry workshops, ergo-therapy, on farming of egg-laying hens and fattening chickens, farming of vegetables in greenhouses and in the open. For these jobs, they receive monthly financial remuneration in the range of 5 to 150 KM (2,5 to 75 EURO).

In the Nahorevo institution, residents are engaged in sports activities, social-therapy, art workshops and different clubs. They receive compensation occasionally from the sale of works and products exhibited as part of the work-occupation therapy. Only one person receives 100 KM (50 EURO) monthly, while five residents receive between 5 and 10 KM (2,5 to 5 EURO) occasionally. As for other types of compensation, residents occasionally receive packages and letters of thanks for their work. In the Bakovići institution, residents are engaged in activities related to maintenance of premises in the laundry room, hairdressing room, canteen, service of technical maintenance, wood shop, library, etc. Out of the total of 372 residents accommodated in this institution, 273 of them are engaged in jobs inside the institution, and three residents are employed outside of the institution. For their work, 141 residents receive between 5 and 30 KM (2.5 to 150 EURO) monthly, and the residents working in the canteen receive 200 KM (100 EURO) monthly. Periodically, as a form of motivation for work, field trips are organized during summer vacations, etc.

Therefore, residents accommodated in social protection institutions in the B&H Federation are mostly employed inside institutions in sheltered workshops, where they do not receive regular financial remuneration for their work, and if they do receive it, the amounts are minimal. From the named information, it is evident that the right to work of residents that are in institutions for social protection is violated. Just the fact that for example in the institution Nahorevo they state that the residents are employed in sports activities, socio therapy and similar activities, demonstrates the misunderstanding of the management of the institution which implies employment of residents, as well as its importance. Engagement in the maintenance of the institution in which they are accommodated and the optional and sporadic payment of fees that are not always in cash are perceived by the staff of the institution as employment. Besides that it is questionable if these residents, who are work occupied in institutions, have signed any working contracts or service contracts and by that have legally acquired the status of employed persons. Moreover, it is evident that with a large number of residents deprived of their legal capacity in institutions it is impossible to sign a working or a service contract.

While some residents are satisfied with the services they receive in sheltered workshops, the majority of them are not. They are often bored, frustrated or angry over limitations imposed in segregated environments. This is exactly the type of situation that can lead to undesirable behaviour of residents, which automatically decreases their chances to work in a realistic working environment (according to trainers' assessment). Without a possibility of employment, there are very few chances that residents can have satisfactory lives, and they will also have less money and fewer opportunities for building the sense of own value and socialization. Very often, these persons remain in their parents' homes, while their peers live in their own homes and make their own living.¹³³

Attitudes of the Public and Employers towards Persons with Disabilities

Authors of numerous research studies maintain that the unfavourable position of persons with disabilities in comparison to the general population is, among other things, a consequence of the negative attitude of the society toward them. The social position of persons with disabilities primarily depends on their position in the process of work. According to results of numerous research studies, persons with intellectual disabilities have an especially unfavourable work-social status, since they are the first to lose a job and the last ones to be re-employed. That is especially expressed in the countries with prevailing unemployment,¹³⁴ and Bosnia and Herzegovina is in such a situation.

Although it is not possible to make general conclusions on the attitude of employers toward persons with disabilities due to poor feedback of companies, the obtained data could still confirm the mainly negative attitude of employers toward these persons. Namely, the very lack of interest of companies in this topic can indicate their lack of tendency and lack of motivation for employing persons with disabilities. Although all of them stated that they are aware of the relevant law, it is questionable to what extent they respect its regulations, especially in the B&H Federation. Out of 15 companies from B&H, eight of them have employed persons with disabilities (120 persons, predominantly hearing impaired persons and physically "disabled persons" – disabled war veterans), and no company has employed a person with intellectual disabilities. As a reason for this, they most often state that working conditions have not been adapted to persons with intellectual disabilities, meaning that jobs often require a quick response in different situations and the ability to work under pressure. All companies, except for one, state that they would rather employ a person with a disability than pay a fine to the Fund. Most companies stated that, if they were to employ a person with disability, they would primarily employ a person with a physical disability (ten companies), while persons with intellectual disabilities and persons with psychological disorders were their last choice. Consequently, we can assume that the prejudice and stigma is mostly expressed towards persons with intellectual disabilities. The best way to reduce and to eliminate prejudice is by getting positive experience with persons towards the existing prejudice. However, considering that persons with intellectual disabilities have the least chance to be employed, it is hard to remove the prejudice in this way, because they do not get the chance to show their abilities and qualities at work. Union SUMERO continuously provides support to persons with intellectual disabilities to find a job according to their abilities and interests. As a result, in 2011, cooperation between Cantonal Public Communal Company Pokop and Cantonal Public Communal Company Park was established, and six persons had work occupations for a certain period of time (service contract). Therefore, persons with intellectual disabilities can find employment, they just need support and representation in certain situations and steps of finding a job, but also it is necessary to constantly work with them on developing skills needed for efficient self-advocacy.

According to Uspon's experiences, the main obstacles for employment of persons with disabilities are social prejudices as well as discrimination against this population. That is the reason why it should be explained that persons with disabilities are not persons with special needs, since they have the same needs as all other employees – a need to provide for their basic existence, a need for communication and companionship, for respect and recognition, a need for education, advancement, as well as the need for self-realization. The only difference is that persons with disabilities sometimes fulfil their

¹³³ Ibralic, Fata and Smajic, Melika. 2007. Persons with intellectual difficulties: contextual approach.

¹³⁴ Skocic, M., Sanja and Kis – Glavas, Lelija. 2010. Working and social competence of persons with intellectual difficulties. Employers' reasons for not employing such persons.

needs in a different manner – for instance, they need different arrangement of working space, a different amount of time to successfully complete a job or a different manner of communication. That is certainly not a reason not to take into serious consideration persons with disabilities when it comes to employment. They should under no circumstances be seen as a burden or bad workers. On the contrary, research on this topic among employers indicates that persons with disabilities are loyal workers, they are absent from work less frequently and they stay in one position longer. In addition, their presence often increases the work morale in an organization, motivating other employees to work harder and show more initiative. One of the main objectives of leaders of an organization and human resources sector is to create sustainability of a work collective, meaning to secure the “right people in the right jobs” in the long-term. Having in mind the mentioned results of research, persons with disabilities can significantly assist with the achieving of a set goal.

Example of Good Practice of Employment

The only social company on the territory of Bosnia and Herzegovina that has, for the last three years, been successfully performing professional rehabilitation, training and employment of persons with disabilities is the Uspon company, formed by the SUMERO Association. The mission of Uspon is economic emancipation and social inclusion of persons with disabilities that are subject to the risk of poverty. With its activities, Uspon wishes to provide persons with the most severe forms of disabilities a possibility to obtain opportunities and resources necessary for full participation in economic, social and cultural life, as well as enjoying the living standard and welfare that are considered normal in the society in which they live.

One of numerous projects implemented by Uspon is the first and only website for employment of persons with disabilities in the region - Uspon.ba, working on creation of work profiles of persons with disabilities, online and offline recruitment of candidates, education, training of employees and employers, staff leasing, project management and HR consulting. This has made information about employment of persons with disabilities available to the wider social community.

Life story of M.R.

I was born on July 1981 in Zenica. I grew up in Home Family in Zenica and I have been there until I was six. After that I was transferred to the institution Mjedenica in Sarajevo because of further education and there I finished primary school. I finished secondary education and vocational training in 2000 and I got the title of a chef, but I never got the chance to work in my profession.

I was in the institution Mjedenica until I was 18, respectively until I was an adult. After my 18th birthday, I had to leave the institution Mjedenica and one family from Sarajevo took care of me. I spent 4 years at this family until I finally tried to be independent, where I rented a flat to see how things will go. Immediately I started to look for a job but, unfortunately, I had no luck. Seven years have passed since I graduated high school and I was constantly looking for a job, but I simply could not find anything until 2006. Then I got the chance for my first employment over at Union SUMERO on the project “Job for disabled” where we produced old souvenirs from clay. I worked on this project for one year and I was again unemployed. Again, I tried everything to get a job but could not find anything. Within the association Oaza I got a chance in 2011 over the social enterprise Uspon to work and it was training for manufacturing picture frames. The training lasted 8 months and during this time we were paid and it was very interesting and pragmatic. Regarding to the fact that I am living alone, that I take care of myself, a job is essential for me. After the work for Uspon I got a chance on July 2011 to be employed as a spokesperson of Union SUMERO for persons with intellectual disabilities, where I still work. My job as a spokesperson is to fight in the best way for the rights of persons with intellectual disabilities, to present the work I do in the best way during media campaigns of Union SUMERO. Within my job, I work on a unique design of the UN Convention on the Rights of Persons with Disabilities that will be in easy-to-read and understand format. My colleagues at work have accepted me very well and I have my own desk, my own computer where I work. The fact that every person who finishes his or her education, can't find an adequate job for which they get qualified for, I must say that I'm very happy that I got a chance to work at Union

SUMERO and I think that this job will contribute to a better of my position in the society. I hope I can stay and work longer here so I try to prove the confidence of my colleagues. I hope to get a permanent job someday and never to return to the previous state, which is not to work and to depend on others. Every person needs equal opportunities while looking for employment according to their abilities. It's much easier when I have a occupation and I feel better when I work and not have to worry for paying the rent, utilities and other expenses.

Conclusion

B&H is facing a complex economic-social situation and an escalating problem of unemployment, while persons with disabilities, in that context, are most distinctively faced with marginalization by institutions regardless of the fact that the country in 2003 adopted the (UN) Standard Rules for the Equalization of Opportunities for Persons with Disabilities. The lack of interest of employers in employment of such persons, prejudices concerning their realistic work ability and discrimination make the already difficult position of persons with disabilities in the B&H society even more difficult. The Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska, which has been in force for seven years, has largely influenced the launching of a process of employment of persons with disabilities. However, the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the B&H Federation was promulgated in 2010.¹³⁵

Although some progress has been made concerning the employment of persons with disabilities after adoption of this law at the B&H Federation level, the law is not defined with sufficient details. Namely, one of the shortcomings is that it does not define which body is responsible for monitoring and imposing penalties and thus the law is basically non-applicable and is soon to be changed and amended. A positive side of the law is the establishment of the Fund for Professional Rehabilitation and Employment of Persons with Disabilities of the B&H Federation.

By summarizing the situation regarding persons with disabilities and their employment, we can conclude that efforts and changes are being made, but not sufficiently and without a strategy elaborated in details. Every law, decision or legal act is in fact just a dead letter, and because of such treatment persons with disabilities have become passive members of this society. The best way to resolve or at least minimize this problem is to launch social entrepreneurship in Bosnia and Herzegovina, by encouraging companies to be socially responsible, which includes raising of awareness about the benefits that social entrepreneurship offers to individuals, the community, companies and the government, development and application of know-how and support for projects of support to business start-ups with practical advice and locating of development funds for social projects with partners, connections and partnership between social organizations, governmental institutions and communities with the goal of development and exchange of new approaches to resolving of social, economic and ecological problems through social entrepreneurship.¹³⁶

Through a well thought out program of work training, production quotas directed toward stimulation, loans and/or subsidies for small enterprises, tax relief and/or other technical or financial assistance, persons with disabilities can have better access to employment on the labour market. Employment with support or smaller forms of protected employment may be an alternative only if it is not possible to meet the needs of persons with disabilities on the open labour market. The existing system of professional orientation and work/craftsmanship training is based on an obsolete approach to protected employment and training that is based on medical diagnostics rather than selection and abilities.¹³⁷

Although significant progress has been noticed through financed programs of supported employment, the majority of persons with intellectual and other development difficulties, if they work at all,

¹³⁵ Leaflet Ten Steps to Full Implementation of Law, Coalition MOGU, HOCU, ZNAM.

¹³⁶ Experiences of Belma Karkelja, director of Uspon.

¹³⁷ Axelsson, Charlotte, Granier, Pascal and Adams, Lisa. 2004. Beyond de-institutionalization: the unsteady transition towards an enabling system in South East Europe.

work in sheltered workshops. Conducted research clearly indicates that the employment of persons with disabilities, and especially persons with intellectual disabilities, is not on a satisfactory level.

Recommendations

Specific directions and measures that need to be undertaken to bring about full implementation of Article 27 of the UN Convention on the Rights of Persons with Disabilities, and which refers to work and employment:

- Assets of the Fund for Professional Rehabilitation and Employment of Persons with Disabilities in FB&H should be directed and distributed to encourage employment without discrimination based on the type of disability. Orient actions of the Fund towards development of incentive measures for employment, self-employment and remaining employed and making progress in the service;
- Considering that entity funds for professional rehabilitation and employment of persons with disabilities are not mediators of employment, it is necessary to establish agencies for retraining and employment within the entity ministries that will act in cooperation with the Fund and which will be connected with the educational institutions and the labour market. Acting of the agencies will make available programs for professional training, retraining and developing working skills of persons with disabilities;
- Ensure the implementation of the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in FB&H with continuous monitoring of respecting measures for employment of persons with disabilities according to the quota system anticipated by this law. In relation to this, constant updating of databases of firms that are subject to this law is necessary;
- Establish a database of unemployed and employed persons with disabilities;
- Establish cooperation between educational institutions and the labour market with the purpose of identifying professions that are aligned with the needs and abilities of children and persons with disabilities, as well as to harmonize programs of educational processes with the needs and possibilities;
- Inform all employers about the rights and obligations foreseen in the Law on Professional Rehabilitation, Retraining and Employment of Persons with Disabilities in FB&H as well as the potential and skills of persons with disabilities in the open labour market;
- Increasing of awareness of persons with disabilities about the importance of their involvement in the labour market;
- Develop programs for professional retraining, employment and specialization, with enabling access to programs of life-long learning for persons with disabilities.

ANNEX

Methodology

With the purpose of collecting data the following methods were used:

1. Analysis of documents
2. Questionnaires

2.1 *The questionnaire for determination of the status of service quality in social protection institutions in FB&H* consists of 292 items divided in four segments: 1. General information about the institution (information about the institution and the management, rulebooks, procedures and principles about the work of the institution); 2. Information about persons with disabilities; 3. Information about the staff in the institution; 4. Conditions in the institution (physical living conditions in the institution, diet, activities, treatment of accommodated persons in the institution, measurements of protection, contacts, health protection).

The research study was participated in by representatives of five social protection institutions in FB&H: Institution for mentally-disabled children and youth Pazaric in Pazaric, Institution for Persons with Mental Disabilities Bakovici in Fojnica, Institution for the Persons with Mental Disabilities Drin in Fojnica, CPI Home Social and Health Care for Persons with Disabilities and Other Persons – Nahorevo¹³⁸ in Sarajevo, Centre for the Reception of the Old and Infirm Persons and Homeless Dujce¹³⁹ in Doboj Istok. The information was collected in cooperation with the federal inspector for work and the Federal Ministry of Labour and Social Policy. In all institutions during the filling out of the questionnaires the whole expert team of the institution was present, as well as the director, except in the institution Pazaric where in the expert team there was no medical expert.

2.2 *The general questionnaire* consists of 98 units and with it information was collected regarding the number of persons with intellectual and psychological disabilities who live in the local community in FB&H, and who have been deprived of legal capacity. participated total of 130 parents/guardians of persons with disabilities participated in the research in four towns in FB&H: Bihac, Zenica, Bugojno and Mostar. Information was collected in cooperation with civil society organizations for support of persons with intellectual disabilities, which are members of Union SUMERO.

2.3 *The questionnaire about investments of foreign organizations for cooperation and development within the embassies in B&H in reconstruction of institutions for residential care.* This questionnaire consists of three units which question the investments in development and reconstruction of institutions for residential care, and investments for support to persons with disabilities and intellectual disabilities from 2005-2010. The following organizations took part in the research: GIZ office Sarajevo – Deutsche Gesellschaft für Internationale Zusammenarbeit, United States Agency for International Development (USAID), AECID – OTC Balcanes – Spanish Agency for International cooperation, The French Embassy, and the Swiss Cooperation Office Bosnia Herzegovina. The questionnaires were sent and received back by e-mail.

2.4 *The questionnaire for regular primary schools* consists of ten units. With this questionnaire information was collected about the number of children with intellectual disabilities in regular schools, about the creation of individualized educational programs, personal assistants and professional staff training. Thirty-two regular primary schools took part in the research from Canton Sarajevo. Questionnaires were filled out by directors and school teachers. Questionnaires were sent and received back by post and e-mail.

2.5 *The questionnaire for homes for children* consists of six units. With this questionnaire information was collected about the number of children with intellectual disabilities who reside in homes, and about their involvement in inclusive education. The research study was participated in by five homes from B&H: Home for Children and Youth Hindered in

¹³⁸ The founder of the institution is Canton Sarajevo who secures funds for performing activities and supervises the work of the institution.

¹³⁹ The institution is registered as domestic, non-government and non-profitmaking organization with a field of action on the territory of whole B&H.

Development Prijedor, Home for Children with Difficulties in Physical and/or Psychical Development Marija Nasa Nada, PI Children's Home Mostar, PI Dom-porodica Zenica and Children's Home Duga- Kulen Vakuf. Questionnaires were sent and received back by post and e-mail.

- 2.6 *The questionnaire for employment bureaus* consists of four units related to the realization of support programs for employment of persons with disabilities in the open labour market with a special emphasis on employment of persons with intellectual disabilities. The research was participated in by the Federal Employment Bureau, the Bureau for Employment RS and the Labour and Employment agency B&H. Questionnaires were sent and received back by post and e-mail.
- 2.7 *The questionnaire for CSOs* consists of ten units related to work engagement of persons with intellectual disabilities in CSOs, whether it is about employment in sheltered workshops or in other jobs in the organization. Of a total of 42 sent questionnaires, 17 organizations from B&H took part in the research. Questionnaires were sent and received back by post and e-mail.
- 2.8 *The questionnaire on attitudes of employers* towards persons with intellectual disabilities consists of 27 units that relate to employment of persons with disabilities, with a special emphasis on employment of persons with intellectual disabilities. Of 70 questionnaires sent to firms in B&H, and which according to the legislation should employ persons with disabilities, 15 took part in the research. Questionnaires were sent and received back by post and e-mail.
3. *The semi-structural interview* with the director of the public institution Cantonal Centre for Social Work in the Canton of Sarajevo and was focused on information about persons deprived of legal capacity and placed under guardianship.

KOSOVO

Structure and Functioning of Public Institutions in Kosovo

Kosovo's new constitution as passed by parliament took effect on 15 June 2008. The constitution defines the governing political system as a parliamentary republic, and states that elected members of the parliament have the ultimate authority to pass laws. The government must present its program to the parliament and must provide information on its activities, plans and achievements whenever the conditions for summoning a cabinet meeting are met. Consequently, high-ranking government officials such as the prime minister, other ministers, permanent secretaries, directors of ministerial departments have the authority to initiate the writing of laws and other legislative documents, including government priorities, strategies and attempts at fixing legislative loopholes.¹ The process of drafting legislation must be accompanied by an analysis of the proposed law's financial soundness, compliance with EU standards, and a conceptual description.²

The mandatory consultation process, which involves input from numerous government stakeholders and legislative bodies, includes consultations with the Gender Equality Office and the Office of Good Governance. The latter is directly associated with the Office of the Prime Minister; its role is to ensure the promotion and protection of human rights. In addition, the government body originating the proposed laws and bylaws must hold public hearings on the content of the proposed laws, with an emphasis on input from non-governmental organizations directly affected by the proposal. However, the approved government regulation on the drafting or initiating of laws and bylaws does not foresee the possibility for civic groups or communities to act as an originating body for legally-binding or administrative documents, hence expanding the possibilities for concerned communities to focus the government's attention on a specific issue. Moreover, due to Kosovo's tight consolidated budget, more often than not financial feasibility may serve as an excuse for the government to lag behind in responding to problems affecting small groups of people.

Kosovo's population

According to the most recent census (mid-2011), Kosovo's population is 1.73 million people living in 295,070 households.³ Most households consist of a large number of members, with approximately two out of three households consisting of five or more persons. There are no reliable data on the number of citizens with disabilities in Kosovo, but the general assumption is that the number is approximately 150,000.⁴ It is estimated that around 42,000, or one fourth of the population with disabilities, have intellectual or learning disabilities.⁵

Current Status of UN Convention on the Rights of People with Disabilities

Kosovo is one of the world's few countries not to have signed, and consequently neither ratified, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, or CRPD). As Kosovo's institutions progress toward becoming members of international treaties and organizations, there is a consensus that certain standards must be met and a particular road map followed. However,

¹ Regulation of Rules and Procedures of the Government of Kosovo, No. 09/2011.

² Ibid.

³ Preliminary 2011 census results, Statistical Office of Kosovo. The census results include data from 34 municipalities. The 2011 census was not carried out in three northern municipalities inhabited predominantly by the Serb community.

⁴ Strategy and Action Plan on Human Rights of the Republic of Kosovo 2009-2011, Office for Good Governance, Prime Minister's Office.

⁵ Broad Survey of Persons with Disabilities in Kosovo, UNDP/Prime Minister/Office of Good Governance, 2011.

in terms of meeting the standards established by the CRPD, no explicit monitoring mechanisms have been put in place. Therefore, the government's commitment to achieving significant results in this field must be viewed with some scepticism.

Kosovo National Disability Action Plan

In 2008, the Government of Kosovo accepted a proposal for preparing a national plan for people with disabilities. Based on the Kosovo government's commitment to serve all communities in Kosovo, the National Disability Action Plan for the Republic of Kosovo – 2009-2011 (NDAP) was compiled. The Kosovo government has assigned the Prime Minister's Office for Good Government (OGG) to coordinate and manage the production of this report, which is meant to serve as the focal point for all organizations involved in the process.

The National Disability Action Plan outlines the Kosovo government's involvement in setting a framework for policy makers and disabled organizations to compile, implement, monitor and evaluate past activities and new strategies for promoting the equal integration of disabled people in society. The main principle of this strategy is the integration of CRPD objectives and other international standards and conventions into the first national framework of policies on people with disabilities.

The National Disability Action Plan represents a strategy for aligning Kosovo's laws and practices with those in developed countries, based on the eight general principles of supporting the human rights and active participation of people with disabilities in Kosovo as contained in the CRPD. The strategy anticipates organizing activities in six distinctive pillars: health, education, employment, social protection, accessibility, and statistical data. Each pillar is assigned numerous objectives and activities that need to be addressed; in many instances, it also defines indicators for measuring progress.

Terminology

Many government documents, including valid laws, use inappropriate terminology when referring to people with disabilities. In addition, legal and administrative documents produced by the Kosovo government do use a uniform terminology, often failing to acknowledge the importance of providing clearly defined terms and concepts related to the issue of disability.

The Kosovo National Disability Action plan has adopted the UN definition of disability. It also envisions this definition serving as the cornerstone of the action plan and future national legislation. By failing to address the definition of disability at an earlier stage, legislation and government activities have failed to apply a uniform framework. Moreover, different ministries use different terminology and definitions.

EQUAL RECOGNITION BEFORE THE LAW

Legal and Policy Analysis

Equality before the Law

Kosovo's constitution recognizes equality before the law as a fundamental right. It establishes equal treatment of all communities before the law, and recognizes the need for accommodating international human rights standards when defining personal liberties and protections. Article Three ensures that the

public authority [...] shall be based upon the principles of equality of all individuals before the law and with full respect for internationally recognized fundamental human rights and freedoms, as well as the protection of the rights of and participation by all [...].

The country's constitution defines equal treatment before the law in other sections as well. In terms of personal rights and freedoms, it also stresses the principle of equality before the law. It is not permitted to discriminate anyone on the basis of personal status, including disability. When it comes to the interpretation of human rights, the constitution foresees the enforcement of court decisions of the European Court of Human Rights. It also envisions the implementation of several international documents and agreements related to the protection of human rights, which would receive priority over domestic laws or other legislative acts regulating the functioning of public institutions. However, whereas the international documents mentioned in this article of the constitution protect and promote the rights of several vulnerable social groups, the article fails to mention any internationally recognized document promoting the rights of people with disabilities.⁶

Equality before the law is contained in several other legal documents as well, such as the anti-discrimination law,⁷ which has been in effect since 2004. This law was passed with a recognition of the need to prevent and combat discrimination and to promote the equal treatment of Kosovo's citizens under the rule of law. The law specifically bans the discrimination of any person or persons based on mental or physical disabilities.⁸ Although the law has been in place for many years, its implementation and the achievement of the desired results remain a serious challenge.

Initiating Court Procedures

Issues pertaining to the pursuit of individual, family or other rights are covered by the Law on Non-Contested Procedure,⁹ which entitles individuals and organizations to initiate a case that requires judicial intervention in defending rights that have been threatened, revoked or breached.¹⁰ In addition, government institutions are also entitled to initiate court cases that under this law relate to this entitlement as well. The law further provides for special court protection of people "who are not able to defend their rights and interests,"¹¹ making the court system one responsible stakeholder for defending the rights and interests of marginalized social groups, including people with disabilities.

Furthermore, people who have been deprived of procedural eligibility may pursue their rights and defend their interests if the court grants them eligibility and if the person capable of understanding the meaning and consequences of such action.¹² In other words, people who have been deprived

⁶ More specifically, Article 22 of the Constitution of the Republic of Kosovo recognizes several international legal documents promoting human rights, including protection against discrimination and rights of national minorities, women, and children.

⁷ Official Gazette of the Republic of Kosovo, No. 14/07, The Anti-discrimination Law, No. 2004/3.

⁸ Ibid., Article 2.

⁹ Official Gazette of the Republic of Kosovo, No. 45/09, Law on Non-Contested Procedure, No. 03/L-007. In line with common practice (e.g. OSCE), this report refers to the "Law on Out Contended Procedure" as the "Law on Non-Contested Procedure".

¹⁰ Ibid., Article 4.

¹¹ Ibid., Article 6.

¹² Ibid., Article 8.

of legal capacity¹³ may initiate a non-contested procedure for reinstating their legal capacity, may initiate court proceedings for regaining rights that were taken away unlawfully, or may pursue their best interests in a given situation with the permission of the court. Court decisions based on Non-Contested Procedures are subject to appeal, which must be processed along with an explanation for the appeal. First-instance appeals are attributed to the first-degree court that treated the matter at hand. After reviewing the complaint, if the first-degree court does not overturn or change the initial verdict, then all the documentation is sent to a second-degree court for dealing with the case further.¹⁴ Unless the court rules that the delivered verdict shall become effective immediately, the verdict cannot be implemented or executed for a period of 15 days.¹⁵ On the other hand, the Law on Contested Procedure¹⁶ defines in detail procedures related to civil disputes in court litigation and civil courts. The law emphasizes that those persons who are fully capable of acting on their own may undertake actions in a procedure (procedural right).¹⁷ The law further describes the procedures in which litigations must be initiated, providing a framework for the general public and the courts as to the requirements the courts must follow when settling civil disputes between individuals and/or organizations. The law states that people without legal capacity shall be represented by a legal representative.¹⁸

Legal Capacity: Deprivation and Reinstatement by Court Decision

Kosovo law makes it possible for people to be deprived of legal capacity. The Family Law establishes that adults may be deprived of legal capacity if they lack full or partial ability to carry 'normal judgment (diagnosed mental illness, mental retardation, or any other similar cause) as a result of which they are incapable of looking after their rights and interest'¹⁹. Partial deprivation of legal capacity is intended for those who put themselves or others in extreme danger as a result of their mental illness, mental retardation, age-related disability, or disability arising from drug or substance abuse.²⁰ Based on these provisions, we may state that partial deprivation of legal capacity is intended only in circumstances when a person puts him or herself or others in extreme danger due to the stated reasons, whereas full deprivation of legal capacity is enacted when a person lacks the ability for normal judgment, as a result of which he cannot defend or pursue his rights and interests. The court exercises the right to rule on full or partial deprivation of legal capacity, and informs the Centre for Social Work that it must assign a guardian within 30 days.²¹ The responsibilities of the custodian body²² extend to ensuring the personal well-being of the person who has been deprived of legal capacity by monitoring his living conditions and supervising the condition that led to his loss or limitation of legal capacity.²³

Court decisions on the deprivation of legal capacity also rely on provisions found in the Law on Non-Contested Procedure, which covers both the deprivation as well as reinstatement of legal capacity and according to which, a person is deprived of his ability to act when 'a person of adult age [...] is not in a condition to look after his rights and interests'.²⁴ The law also lists the people or institutions that can initiate the procedure for taking away or reinstating legal capacity. One positive aspect of

¹³ In line with the uniform and consistent use of terminology throughout the report, we here replace the phrase "capacity to act" frequently found in Kosovo legislation with "legal capacity". The use of common expressions has been agreed upon based on the consensus that use of legal terms should reflect more accurately the type and capacity of described notion.

¹⁴ Ibid., Article 20.

¹⁵ Ibid., Article 19.

¹⁶ Official Gazette of the Republic of Kosovo, No. 38/08, Law on Contested Procedure, No. 03/L-006.

¹⁷ Ibid., Article 74.

¹⁸ Ibid., Article 75.

¹⁹ Official Gazette of the Republic of Kosovo, No. 4/06, Family Law of Kosovo, No. 2004/32, Article 223 (1).

²⁰ Ibid., Article 223 (2).

²¹ Under the Law on Social and Family Services (Official Gazette of the Republic of Kosovo, No. 12/07, Law on Social and Family Services, No. 02/L-17), all municipalities in Kosovo possess centres for social work. These are under the jurisdiction of the Ministry of Labour and Social Welfare, and serve as the primary units for the provision of social services. Among other duties, the centres for social work are responsible for organizing the institution of custodian body (Guardianship Authority, as delineated in Article 7.2 of this law).

²² In this publication, we have replaced the term "custodian body" as commonly used in documents with "guardianship authority".

²³ Family Law of Kosovo, Article 228 (1).

²⁴ Ibid., Article 31 (1).

this law is that it includes the affected person who had his legal capacity taken away among those people who may initiate a procedure for reinstating legal capacity.²⁵ The court may hold a hearing at the institution in which the person is residing, and the court has the authority to communicate with this person in private.²⁶ Legal capacity is reinstated via a court decision if it has been proven to the court that the reasons for the full or partial removal of legal capacity have ceased to exist.²⁷ In both instances – depriving and reinstating legal capacity – the procedure may be initiated by delivering a proposal to the court containing supporting facts and documents, as well as probative means relevant to the claim.²⁸ In the presence of the judge, three medical experts from the relevant fields perform a psychological evaluation and assess the person's mental capacity for sound judgment.²⁹ The law does not define the criteria to be used by the medical experts for establishing a lack of sound judgment. The civil registry office and the real estate registry are informed on the court's decisions.³⁰

(Restriction of) Rights of People Deprived of Legal Capacity

There are reports that people in institutional care are not included in the distribution of inheritance.³¹ This may be due to a lack of information regarding their rights or, if they are under guardianship, their purposeful exclusion. As for persons under guardianship, the guardian is required to send regular reports to the guardianship authority regarding the state of the persons under guardianship, including property issues.³² Furthermore, the Law on Contended Procedure requires persons whose legal capacity has been removed or reinstated to immediately record the property they own.³³ Although the aim is for their assets to be recorded and acknowledged, the law does not specify which assets to include – movables, immovables, or other assets. In addition, within the context of property inheritance (in which property is as a rule inherited by later generations from earlier ones), this article may serve as an auxiliary legal path for people whose right to a family inheritance was restricted to file suit for enforcing such a right.

Deprivation of legal capacity involves the enumeration of those rights that the affected person is restricted from pursuing. Two of the most important rights that are restricted relate to managing social welfare payments and the right to vote. For instance, if someone receives a disability pension, then that person cannot receive this assistance directly. Instead, the assigned guardian receives the money and is responsible for disbursing the money on a monthly basis. In addition, all Kosovo citizens with legal capacity have the right to vote. Both the media and election monitoring organizations have documented irregularities, often without any discrimination, in voting by residents of community-based homes and rehabilitative institutions during all elections in Kosovo since 2000. Some people have voice concerns that the votes of such people have been manipulated.³⁴ It is the responsibility of the courts to provide the Central Electorate Commission with the number of and details on persons who have been deprived of legal capacity.³⁵ This means that the persons on that list cannot vote unless they have had their legal capacity reinstated. In addition, people who have been deprived of legal capacity can marry only if they submit a request to the court and have received approval from their parent, guardian or the guardianship authority.³⁶ According to the Law on Family, a child born to

²⁵ Ibid., Article 32 (g).

²⁶ Ibid., Article 38.2 and 38.3.

²⁷ Ibid., Article 31 (2).

²⁸ Ibid., Article 34 (1).

²⁹ Ibid., Article 40.1.

³⁰ Ibid., Article 47.

³¹ Human Rights Situation in Mental Health Institution 2011, Kosovo Rehabilitation Centre for Torture Victims, 2011.

³² Law on Non-Contested Procedure, Article 252.

³³ Ibid., Article 35.

³⁴ The trustworthy local newspaper Zeri reported on serious allegations that the votes cast by residents of the Special Institute in Shtime have consistently gone to one specific political party, including the most recent national elections in late 2010. Moreover, despite their limitations on voting, even residents without legal capacity have been allowed to vote. The situation was not clarified even when elections were administered by the Organization for Security and Cooperation in Europe's Kosovo mission. Accessed November 2011. <http://www.zeri.info/artikulli/1/1/17335/votat-speciale-te-shtimes/>

³⁵ Official Gazette of the Republic of Kosovo, No. 31/08, Law on General Elections in the Republic of Kosovo, No. 03/L-073, Article 7.

³⁶ Law on Family, Article 20.

parents without legal capacity must be subjected to court proceedings initiated by the guardianship authority in order to establish whether the child was born within the marriage.³⁷ Moreover, aside from anyone with legal capacity who is at least 16 years of age, parenthood is recognized only to people with partial legal capacity who can understand the responsibilities arising from the recognition of parenthood.³⁸

Diminished Mental Capacity in the Penal Code

The provisional penal code of Kosovo treats and defines the issue of “mental disability, mentally incapable persons and decreased mental ability – including involuntary psychiatric treatment.”³⁹ The provisional penal code defines perpetrators of criminal offences with intellectual disabilities as mentally incompetent if, at the time of the “commission of a criminal offence, he or she suffered from [...] disturbances in mental development that affected his or her mental functioning so that such person was not able to understand or control his or her actions or omissions or to understand that he or she was committing a criminal offence.”⁴⁰

Guardianship Authority

The Family Law regulates the issue of guardianship of people who have been deprived of legal capacity. After ruling on the removal of legal capacity, the court assigns the guardianship over to the guardianship authority,⁴¹ which is a competent administrative municipal body comprised of a group of experts with professional work experience in the relevant field.⁴² Within a thirty-day period, the guardianship authority must provide the person with a guardian, who shall be chosen from among the ward’s family.⁴³ Blood relatives in direct linear ascendancy or direct linear descendents, as well as sisters and brothers of the person under guardianship, are legally required to accept the task of a guardian if they meet all the requirements for guardian as defined by the law.⁴⁴ The main exceptions are based on the guardian’s age, health, or if they have children of their own to look after. People without legal capacity (full or partial) and those whose interests are in obvious conflict with the interest of the ward cannot serve as a guardian.⁴⁵ Also, a person cannot be a guardian if personal features or pecuniary interests may be in conflict with the interests of a guardian and where it is suspected that the relationship with the person under guardianship or natural parents may cause conflict.⁴⁶ In appointing a guardian, the guardianship shall take into account the wishes of the person under guardianship if he or she is capable to expressing his or her interests.⁴⁷ The role of guardian may also be taken on by the guardianship authority itself, if this will be in the interests of the person to be under guardianship.⁴⁸ Although it is not explicitly included in the law, the guardianship authority also serves as a guardian in cases where the person under guardianship has no known family, or if for whatever reason the family fails to exercise its guardian duty.

Practice analysed

Status of Court Procedures on Legal Status Deprivation

A person may be deprived of legal capacity only by a court decision. To date, the justice system in Kosovo, through its municipal and district courts, has not succeeded in developing monitoring mechanisms for systematically collecting, classifying and reporting on court proceedings. As a result, we have no official data at the country level regarding the number of people who have been deprived

³⁷ Ibid., Article 100.

³⁸ Ibid., Article 102.

³⁹ UNMIK’s Regulation No. 2003/26 and Official Gazette of the Republic of Kosovo, No. 44/08, Provisional Criminal Code of Kosovo.

⁴⁰ Ibid., Article 12.

⁴¹ Law on Family, Article 224.

⁴² Ibid., Article 6.

⁴³ Ibid., Article 236.

⁴⁴ Ibid., Article 238.

⁴⁵ Ibid., Article 237.

⁴⁶ Ibid., Article 237.

⁴⁷ Ibid., Article 239.

⁴⁸ Ibid., Article 240.

of their legal capacity. All courts have tremendous case backlogs; visiting them all in order to gather data about court decisions resulting in capacity deprivation would be an arduous task.

We nevertheless managed to obtain some data on the number of people who have been deprived of legal capacity from the Special Institute in Shtime (SISH) and from the municipal courts in Gjakova/Djakovica and Prishtine/Pristina. During the 2007-2011 period, 13 residents at SISH had their legal capacity removed.⁴⁹ Placement in the Special Institute in Shtime or within a community house requires a court decision on the deprivation of legal capacity. Based on the most recent list of residents at SISH and community houses, the ratio between the overall number of residents and those who have been deprived of legal capacity indicated that the latter group is still a minority: only 27 out of 128 residents at SISH and community houses have been the subject of court decisions related to their legal capacity.

On the other hand, between January and August 2011 the municipal court in Gjakova/Djakovica⁵⁰ ruled on six cases of legal capacity deprivation based on a person's disability.⁵¹ In addition, a judge at the Prishtine/Pristina municipal court reported that during the past two years she has heard only two cases of people with intellectual disabilities who were deprived of their legal capacity. Neither of the two individuals was placed in a residential institution.⁵² This information tells us that only a fraction of disabled people without legal capacity are placed in institutions, whereas most of them continue to live in a family setting.

As a rule, during the procedure the judge is supposed to record an interview with the person whose legal capacity is subject of the hearing. There are exceptions to this rule if such communication is not possible. In one court decision for the deprivation of legal capacity that the research team had a chance to review, we encounter a quite terse description of the court's verdict. Although the described activities are in harmony with existing legislation, there is no indication that any safeguard practices were applied in seeking alternatives to the deprivation measures. The ruling implies that the person whose legal capacity was being assessed was present at the hearing, and that the judge communicated with him. However, we know nothing about the nature of this communication, since no transcript was included. As a result, we do not know what the discussion entailed, whether the person understood the process, whether he was informed of the consequences of the hearing, and whether he knew his rights. The court's decision did not call for any review of the decision – in relation to which we should point out that the existing legislation contains no safeguards, not even the possibility for a later review of the ruling.

A further analysis of the court's verdict finds two anomalies that occurred over the course of reaching the court decision and placing the person in the SISH. The first anomaly is that the court's decision uses terminology that is inappropriate to the field of mental disability. Specifically, the laws that the court's decision refers to apply to people who are mentally "sick", whereas the diagnosis obtained from the SISH reveals that the person in question actually has intellectual disabilities. Secondly, in the paragraph describing the legal provisions that formed the basis for the court's ruling, the judge referred to two articles from the Law on Contended Procedure, articles 31 and 40. Article 40 states that a person may be temporarily placed in a healthcare institution for a maximum period of three months. The Special Institute in Shtime is not a healthcare institution, but rather a social rehabilitative institution. Secondly, the court's ruling did not call for any evaluation date or any follow-up procedure within the three-month period foreseen in the article. Both these omissions demonstrate a lack of knowledge about the nature of mental disabilities and a lack of concern that the decision may potentially have a detrimental effect on the defendant.

⁴⁹ Interview with Berat Zhinipotoku, Director at the Special Institute in Shtime.

⁵⁰ The data on court decisions regarding the deprivation of legal capacity were gathered only at two municipal courts in Kosovo: in Prishtine/Pristina and Gjakove/Djakovica. The data presented in this paragraph reflect the number of cases in only these two municipal courts for a limited period of time. Since information regarding the nature of the court's caseload is not reported on a regular basis, we cannot extrapolate the data to the countrywide level. There are 26 municipal courts in Kosovo – the municipalities of Prishtine/Pristina and Gjakova/Djakovica are the most populous and fifth-most populous municipalities, respectively, in Kosovo.

⁵¹ Interview with Ahmet Idrizaj, Gjakova municipal court judge.

⁵² Interview with Drita Rexhaj, Prishtina municipal court judge.

Deprived Legal Capacity: Deprivation of Rights

The inheritance rights of people who have been deprived of legal capacity are only vaguely discussed in the current legislation, leaving open the possibility that their ability to inherit property will be negatively impacted. Normatively, the inheritance courts should remain vigilant if any of the people eligible to inherit property from the deceased has been deprived of legal capacity. However, they inform the guardianship authority of inheritance proceedings only when inheritance proceedings are not held, under the assumption that none of the descendants has requested the court to initiate hearings for considering the inherited property.⁵³ The family members capable of inheriting the deceased's property may reach an agreement on the inheritance and thus exclude the person without legal capacity.

Basically, if a person who has been deprived of legal capacity does not have any family care or other supporters, the chances are that they will be placed in the Shtime Institution or in one of the community homes. Placement in the Special Institute in Shtime does not require any consensus between the guardian's approval and the will of the (future) resident. Consequently, residents do not have much say as to whether they want to be placed in the institution or not, or whether they are willing to undergo treatments prescribed by a doctor.⁵⁴ It is a disturbing fact that none of the release circumstances contained in the Shtime Institution's house rules⁵⁵ view the residents as being eligible for initiating or being a party to proceedings for their release from the institution. Reasons for being released from the institution are if the delegated authority or the resident cannot acclimate to the conditions in the institution, or upon a request from the resident's family members. Along with numerous other detrimental factors, these devastating circumstances have a significant impact on the effectiveness of rehabilitative efforts for the residents at the Special Institute in Shtime and at community homes.

Responsibilities of the Guardianship Authority

One important criterion for placing people with intellectual disabilities in a community home or in the Special Institute in Shtime (ISSH) is a court decision establishing that the person has been deprived of the legal capacity to initiate the enrolment.⁵⁶ In this regard, guardianship authority's performance of its legally mandated duties has been unsatisfactory, as reported by several monitoring visits to persons deprived of legal capacity, in particular at the Shtime Institute. The ombudsperson's office received information on the progress for only two of the Shtime Special Institute's residents, based on a written request.⁵⁷ Other organizations, too, have reported a failure to organize visits and to monitor the progress of persons placed in community homes by the guardianship authority.⁵⁸

As regards the specific tasks of the guardianship authority, its application of legislation governing this capacity has been weak. In early 2011, the Organization for Security and Cooperation's Kosovo mission produced a report based on their observations of the manner in which the Law on Family was implemented by the courts.⁵⁹ The aim of the report was to analyse how cases that were under guardianship were being managed. Although the observers did not specifically record the guardian's obligations towards people who have been deprived of legal capacity, we may assume that the

⁵³ Law on Non-Contented Procedure, Article 153.

⁵⁴ Regulation No. 08/2008 for Internal Organization of Work at the Special Institute in Shtime, Ministry of Labour and Social Welfare, foresees that residents who are prescribed medication by a doctor must take it. If the residents refuse to take the medication, the staff are supposed to inform the doctor about this refusal. The document does not go into further detail as to the standard procedures if a person refused taking the medicine. On the other hand, the same document does not envision compulsory vocational training, and does not even discuss any incentives that may be used to encourage residents to attend training sessions and improve their skills. The discrepancy between the forced medical treatment and the laws and bylaws is unprecedented, and can only be understood as an example of targeting the symptoms of an issue rather than helping to empower the residents establish themselves independently within a community setting.

⁵⁵ Ibid., Article 56.

⁵⁶ Administrative Guideline No. 06/2011, For Work and Placement of Residents, Persons with Mental Disabilities – Delay in Mental Development at the Special Institute in Shtime and in Homes with Community Based, Ministry of Labour and Social Welfare.

⁵⁷ About the legality of refraining people with mental disabilities in Special Institute in Shtime, Ombudsperson's Institution, 2005.

⁵⁸ See for example the report by the Kosovo Rehabilitation Centre for Torture Victims. Human Rights on Mental Health Institutions. 2011.

⁵⁹ Adjudication of family law cases in Kosovo: Case management issues, OSCE mission in Kosovo, 2011.

findings can be projected onto these cases as well. Specifically, the report identifies flaws in case management, in particular in the adjudication of cases “involving dissolution of marriage and cases involving guardianship of and access to children.” The court data reveal a backlog over the past two years in cases involving such issues, which raises the concern whether the court system can meet domestic and international standards for protecting human rights by providing timely, objective and fair access to justice.

Enforcement of the Anti-discrimination Law

Despite the fact that the law on discrimination has been in effect for many years, it does not appear to be having the desired result. Several issues have been addressed by the ombudsperson,⁶⁰ who has reported on the law’s limitations and omissions. According to the Ombudsperson’s report, the functionality of the Anti-Discrimination Law suffers from a poor definition of its components, followed by the unclear role of the legal institutions involved in dealing with such cases. The unclear areas of this law – including the procedures that must be followed when initiating litigation and questions as to which institutions are entitled to deal with such claims – call into question the law’s effectiveness since being passed by the Kosovo parliament.⁶¹ The Ombudsperson’s office has been raising these issues for some time, without any response from judicial or governmental institutions. Equality before the law remains a key reason why the general public seeks out the services of the Ombudsperson.⁶² The Ombudsperson’s office has failed to identify any standard practice in such cases; each individual case is initiated via different institutional and administrative paths.

Conclusion

The basic human rights for all people of Kosovo to act independently according to their own free will is not being faithfully protected by existing Kosovo legislation. The current legislation provides the tools for depriving people of legal capacity by court decision. As a result, people with intellectual disabilities are prevented from pursuing their basic human rights, due to the selective application of deprivation of the right to make decisions about one’s own life.

People with disabilities who are deprived of legal capacity most often face additional obstacles to pursuing other rights, such as voting in elections and managing social assistance received in monetary form. People in institutions who have been deprived of legal capacity face additional barriers, since they are not legally entitled to even initiate the procedure for being released from the institution. People who have been deprived of legal capacity are not re-evaluated on any basis, let alone a regular one, which further diminishes the chances of having a mechanism in place that will ensure continuous efforts on the part of all accountable stakeholders to empower disabled people who have been deprived of legal capacity to exercise their inalienable rights.

The data from the field indicate that the judicial system makes repeated use of the possibility of depriving people of their legal capacity. Other legally binding documents for the promotion and preservation of human rights are not applied at a level sufficient for ensuring that all people can enjoy equal treatment before the law. Supported decision-making is not applied frequently enough during court proceedings on the subject of legal capacity. The legal system does not provide sufficient and conveniently available information for people with intellectual disabilities that might help them understand the process and its the possible consequences, and thus be able to make an informed decision or seek the right to exercise and preserve their integrity and independency.

Recommendations

The Kosovo government needs to review and propose changes in the legal infrastructure pertaining to the deprivation of legal capacity. The Law on Non-Contested Procedure must be amended and Kosovo’s parliament needs to ratify these changes and remove the current restrictions on the

⁶⁰ Ombudsperson’s annual report 2010, Kosovo Ombudsperson Institution, 2010.

⁶¹ Ibid.

⁶² Ibid., page 127.

human rights of disabled people in Kosovo. Moreover, the rights of all disabled people to vote and to independently manage their social benefits must be reinstated as well.

Ratification of the UN CRPD must be an unconditional priority, and the government must ensure that the legislative framework and policies in power are aligned with the principles described in the Convention, thus demonstrating the willingness and ability to adhere to the best practices from other countries and to fully promote human rights. Moreover, it would be a good idea to establish an independent body for developing mechanisms and monitoring the progress in meeting the standards outlined by the CRPD.

The judicial system must maintain a fair balance in terms of the legislation applied during legal capacity deprivation procedures by giving priority to other legally binding documents for promoting equal treatment and promoting and protecting human rights for all people in Kosovo. Judges must be trained to exercise the option of supported decision-making for people whose legal capacity is being assessed, instead of preventing them from participating in decisions affecting their personal life.

Civil society organizations and organizations for people with disabilities should be more active in promoting the rights of disabled people to make decisions on matters that affect them. These organizations should receive support for capacity building, strengthening the resources for generating operational funds, sustainability, and advocacy campaigns. A sustainable and active network of civil society organizations will yield best results in advocating for the equal rights of people with disabilities.

The use of appropriate terminology is something that applies to all aspects of disability policy, not just the deprivation of legal capacity. The terminology contained in Kosovo's laws, including documents issued by the government, must be uniform and provide a clear and accurate description of disability-related issues. It must also not stigmatise, label, use outdated terminology, or employ any form of discrimination.

INDEPENDENT LIVING AND COMMUNITY INCLUSION

Legal and Policy Analysis

Legal Framework

Kosovo's constitution explicitly states that everyone is guaranteed the right to liberty and security.⁶³ People may be deprived of liberty by a court order, or in other cases as envisioned by law. For the most part, people lose their right to liberty if they have committed a criminal act or if there exists reasonable doubt that a lack of restrictions may lead to another criminal act resulting from the person's freedom to act.⁶⁴

Public Health Institutions: Structure and Functions

The organizational structure of Kosovo's new health system is described in the Health Strategy for Kosovo published in 2001, as referenced in the Sectoral Health Strategy for 2010-2014.⁶⁵ This strategy divides medical treatment into three main levels: primary, secondary and tertiary. The provision of professional mental health services in community settings takes place on the secondary level of medical care. These services are offered through regional hospitals. In addition to the geographical distribution of mental health institutions care across the regions in an attempt at providing healthcare services uniformly to areas inhabited by a similar number of inhabitants, we could identify no other attempt at establishing new mental health services.

When it comes to institutions run by the Ministry of Health that provide mental health services to people with psychosocial disabilities, community-based mental health services are offered through seven administrative units established in all regional centres throughout Kosovo.⁶⁶ Each regional administrative unit consists of a mental health centre,⁶⁷ a community integration home, and a unit for the mental health of children and adolescents.⁶⁸ (Centres for the mental health of children and adolescents operate as outpatient services within the main family healthcare centres, and the construction of a separate facility for these units is part of the 2008-2013 Strategic Plan for Mental Health.⁶⁹) Professional mental health services are offered on the basis of community resources and are focused on empowering families of persons with "mental illnesses and disabilities."⁷⁰ Administrative rules further state community integration home cannot accept people with "mental delays, dementias of any kind, addiction, and social cases."⁷¹ As a result, these institutions do not offer services to persons with intellectual disabilities.

The Ministry of Health offers treatment and rehabilitation of people with psychosocial disabilities, whereas the Ministry of Labour and Social Welfare provides services to people with intellectual disabilities. This means that the community-based homes are managed by the Ministry of Labour and Social Welfare (MLSW). The aim of these facilities is to prepare people with intellectual disabilities to gradually become independent and join community life (or for those who have families, to return to their families and earlier place of residence).⁷² To date, seven community-based homes have been

⁶³ Constitution of the Republic of Kosovo, Article 29.

⁶⁴ Ibid., Article 29.2.

⁶⁵ Sectoral Health Strategy 2010-2014, Ministry of Health. Accessed November 2011. HYPERLINK "http://www.msh-ks.org/attachments/281_strategjia.pdf"http://www.msh-ks.org/attachments/281_strategjia.pdf.

⁶⁶ Administrative Guideline No. 07/2009 for Professional Mental Health Services in Republic of Kosovo

⁶⁷ According to the first progress report of the National Plan for Persons with Disabilities in the Kosovo Republic (2009-2011), five mental health centres are in operation in Kosovo.

⁶⁸ Ibid, Article 7

⁶⁹ Ibid, Article 10

⁷⁰ Ibid, Article 9

⁷¹ Ibid, Article 9

⁷² Role of Division in Institutional Care, Department for Social Welfare, Ministry of Labour and Social Welfare.

made operational for adults, plus two for children. The MLSW also manages the Special Institute in Shtime. The community-based homes' initial capacity is 10 persons. The total number of people who receive services at the community-based homes and SISH is 128.⁷³

The rights and duties of all patients in the healthcare sector are established by law.⁷⁴ This law requires healthcare to be adequate, accessible and free of discrimination.⁷⁵ All people are entitled to choose their health practitioner, may seek out a second opinion in order to confirm a diagnosis and/or proposed therapy, may be released from an institution providing round-the-clock care, and may be transferred to another medical institution.⁷⁶ According to the law, medical treatment must respect the person's dignity, privacy, personal integrity and religious affiliation.⁷⁷ Citizens have the right to choose whether they want to undergo a certain treatment, and may leave a health institution voluntarily except in cases when such an action would risk the life or physical safety of others.⁷⁸ The law thus allows medical practitioners to perform only necessary medical interventions.⁷⁹ If a persons with no or partial legal capacity refuses to agree to a necessary medical treatment, then medical institution must first engage the courts in order to obtain authorization to proceed.⁸⁰

In addition, the relevant administrative guideline requires that the existing services be expanded to include additional services such as assistance for people with intellectual and physical disabilities in creating and maintaining healthy conditions for independent living at their home or place of residence.⁸¹ Although the services provided are not seen as being particularly helpful (since they mostly involve basic housekeeping tasks and personal care), it is a positive development to see governmental supporting structures set up with the aim of reaching marginalized groups to be maximum possible extent.

⁷³ Interview with Behxhet Gaxhiqui, Adviser to the Minister and Ministry's spokesperson – Ministry of Labour and Social Welfare.

⁷⁴ Official Gazette of the Republic of Kosovo, No. 13/07, Law on Rights and Responsibilities of Citizens in Health Care, No. 2004/38.

⁷⁵ Ibid., Article 4.

⁷⁶ Ibid., Article 5.

⁷⁷ Ibid., Article 6.1 and Article 8.

⁷⁸ Ibid., Article 10.

⁷⁹ Ibid., Article 6.2

⁸⁰ Ibid., Article 16.

⁸¹ Administrative Guideline No. 13/2010 for the provision of services in community homes for persons with disabilities and delays in mental development, Ministry of Labour and Social Welfare.

The three levels of public health services

Primary:	Family healthcare service		
	Funded by municipal budgets, administered by the Ministry of Local Administration		
Secondary:	Ministry of Health	Institute in Shtime	Ministry of Labour and Social Welfare
		Centre for Integration and Rehabilitation of Patients with Chronic Psychiatric Illnesses	Special Institute in Shtime
		58 psychiatric residents	57 residents with intellectual disabilities
		Psychiatric Disability	Intellectual Disability
	1. Prishtine	1.1 MHC in Prishtine:	
		1.1.1 Ulpiane	
		1.1.2 Podujeve	
		2.1 Community-based integrated house	1.1 Community-based house
		2.1.1 Bresje (Fushe-Kosove)	2.1 Children`s house
		3. Njesia e infermierise	
		4. Mental health unit for children and adolescents	1. Community-based house
	2. Ferizaj	1. MHC in Ferizaj	1. Community-based house
		2. Community-based integrated house	3. Kamenice
		3. Mental health unit for children and adolescents	1. Community-based house
	3. Gjilan	1. MHC in Gjilan	1. Community-based house
		2. Community-based integrated house	5. Decan
		3. Mental health unit for children and adolescents	1. Children`s house
	4. Mitrovice	1. MHC in Mitrovice	
		2. Community-based integrated house	
		2.1 Drenas (Skenderaj)	
		3. Mental health unit for children and adolescents	
	5. Gjakove	1. MHC in Gjakove	
		2. Community-based integrated house	
		3. Mental health unit for children and adolescents	
	6. Peje	1. MHC in Peje	
		2. Community-based integrated house	
		3. Mental health unit for children and adolescents	
	7. Prizren	1. MHC in Prizren	
		2. Community-based integrated house	
		3. Mental health unit for children and adolescents	
Tertiary:	University Clinic Centre		
	Psychiatric Clinic – Supervised by Ministry of Justice		
	Mental Health Centre for Children and Adolescents		

De-institutionalisation

The 2009-2011 National Action Plan for People with Disabilities mentions de-institutionalisation as one activity for transforming the social-protection approach to people with disabilities into a model based on social inclusion. The strategy confirms the need to continue the de-institutionalisation process begun years ago, while reforming the process through the use of international instruments and best practises. This plan called for the Special Institute in Shtime to be closed in 2011. Later activities envisioned by the plan involve developing and implementing policies for preventing the institutionalisation of disabled people by creating community-based services throughout the country. These services are planned as small units or micro-residencies based on a family living model and managed by the private or the public sector. The action plan does not go into further detail as regards alternatives to institutional care, indicating a lack of specific planned actions and of the government's engagement in continuing the de-institutionalisation process by placing residents in community-based independent living facilities.

Analysis of Practice

Medical model versus social inclusion

The dominant approach to treating people with mental disabilities⁸² and intellectual and psychosocial disabilities has been the medical model, which involves placement in a closed mental health institution. Community services were scarce and community-based treatment was almost unknown.

With the rise of new practices for treating people with disabilities, however, various successful inclusive practices imported from abroad have been implemented. In December 2000, about a year and a half after the UNMIK administration⁸³ was installed in the country, a task force was charged with developing an all-inclusive disability strategy, with the objective of aligning local practices with international practice and UN rules and regulations on equal opportunities.⁸⁴ These reforms resulted in few changes in the treatment of people with psychosocial and intellectual disabilities. The old system, which had been based on institutional treatment, saw the development of new practices and legal structures for shifting treatment towards community-based environments, with the aim of social inclusion rather than conventional treatments. However, these reforms have been difficult to implement and have been stagnating. To date, the dominant form of treatment is medical, based on the use of medication and with limited or almost no complementary socio-therapeutic or psychotherapeutic treatment.⁸⁵

Special Institute in Shtime (SISH)

In mid-2011, the Ministry of Labour and Social Welfare issued an administrative guideline defining the organization and functioning of community-based homes and the Special Institute in Shtime.⁸⁶ These two types of facilities offer around-the-clock care to people with intellectual disabilities on the basis of this guideline.⁸⁷ In addition to the elementary care that is provided to the residents of these facilities, the treatment also includes housing and food, medical care and rehabilitation activities.⁸⁸

⁸² Unless otherwise specified, the phrase people with mental disabilities includes all groups of people with mental disabilities. In cases relating specifically to another subgroup, we use other terminology for more accurately describing the type of disability.

⁸³ The United Nations Mission in Kosovo (UNMIK) was established in June 1999. It is the provisional governing body within the territory of Kosovo.

⁸⁴ All-inclusive framework on disability policies in Kosovo, UNMIK's Task force on disability issues, 2001

⁸⁵ Initial Observations on Gaps in Health Care Services in Kosovo, UNKT 2007; Report delineates that there are only .32 available psychologist per 100,000 inhabitants, which compared to other European and regional countries comes last.

⁸⁶ Administrative Guideline No. 06/2011 for working with and the placement of persons with mental disabilities at community-based homes and the Special Institute in Shtime, Ministry of Labour and Social Welfare. This guideline offers additional instructions related a similar Administrative Guideline approved in 2004: Administrative Guideline No. 12/2004 for working with and the placement of residents in the Special Institute in Shtime, Ministry of Labour and Social Welfare.

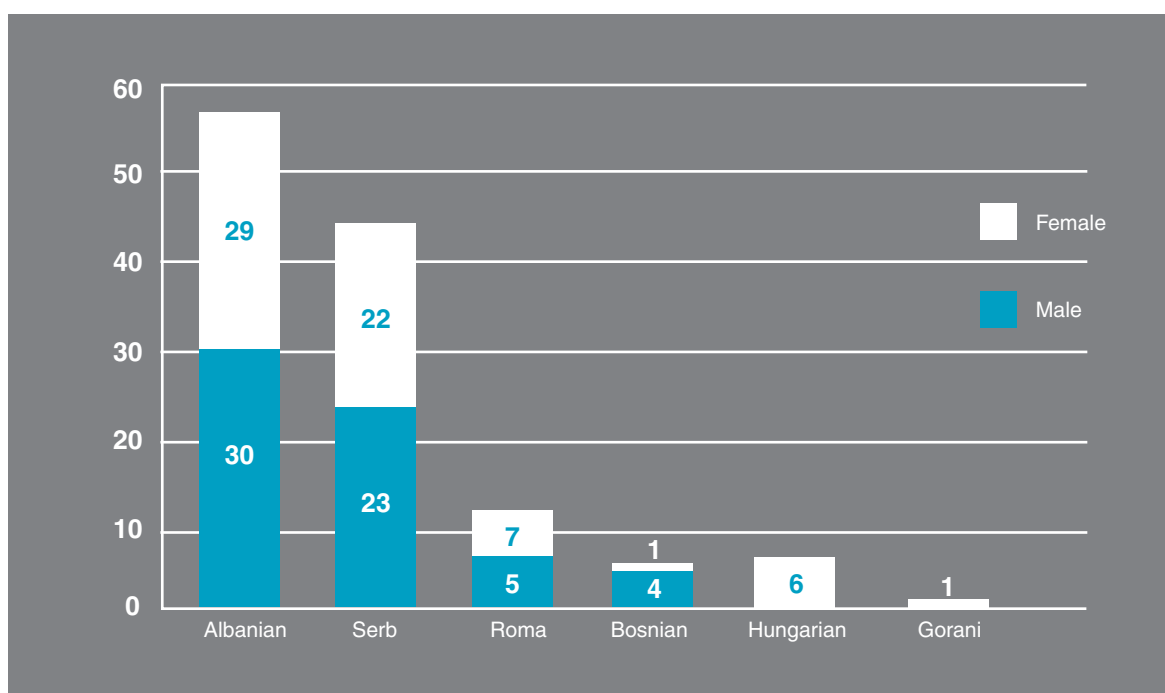
⁸⁷ Ibid., Article 5.1.

⁸⁸ Ibid., Article 5.1.

A key criterion for enrolment in community-based homes and SISH is a municipal court decision on deprivation of legal capacity.⁸⁹ Placement within SISH or community-based home represents another barrier to reintegration into community life: not only are SISH residents (having been deprived of legal capacity) forbidden from initiating a hearing for their discharge from the institution, they also remain institutionalised even if the rehabilitation process at SISH has shown positive results. In order to initiate placement within SISH and community-based homes, the administrative guideline requires the case manager (an appointed social worker from the Centre for Social Work) to provide proof that nobody, including other family members, can look after the applicant.⁹⁰ For each placement, the Centre for Social Work the relevant facility must to reach an agreement as to all the parties' obligations and responsibilities.⁹¹ During placement, the professional staff must monitor the residents' progress and should engage them in the process of preparing for a life outside of the institution – i.e., returning to the community life or entering another form of treatment outside of the institution.⁹² The placement period must form a part of the agreement between the parties and cannot be indefinite. This emphasizes the fact that institutions must be engaged in their residents' rehabilitation.⁹³

Institutional care for people with intellectual disabilities is provided by facilities that are managed by the Ministry of Social Labour and Welfare. The Special Institute in Shtime is the largest institution that provides inpatient treatment, and currently provides services to 56 residents from various ethnic groups (there are 30 Serbs, 11 Albanians, 8 Roma, 5 Bosnians, 6 Hungarians and 1 Gorani); 21 are women.⁹⁴ The vast majority of residents (44) have been in this institution for more than 15 years, which underscores the significant length of stay for all current residents. The following table shows the number of residents, extrapolated by gender and ethnicity, at the Special Institute in Shtime and at community-based homes.

Residents at the Special Institute in Shtime and at community-based homes



⁸⁹ Ibid., Article 6.1.

⁹⁰ Ibid., Article 7.1.

⁹¹ Ibid., Article 9.

⁹² Ibid., Article 11.1.

⁹³ Ibid., Article 11.3.

⁹⁴ Unless otherwise specified, all information obtained regarding institutional care at the Shtime Institute and community-based homes comes from an interview with the SISH's director, Mr. Berat Zhinipotoku.

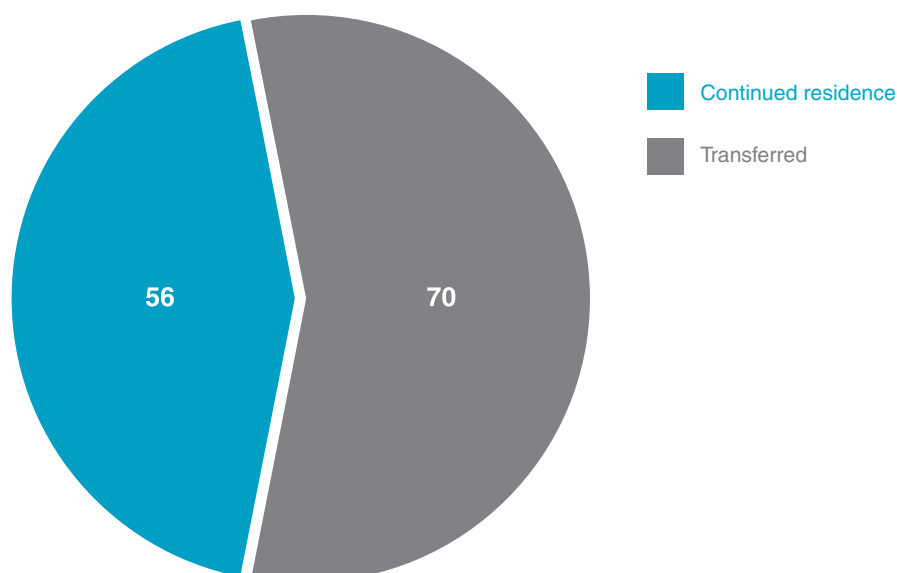
Demographics and health information on the residents of the Special Institute in Shtime

Length of stay	%	Age	N	Type of diagnosis*	N
15 or more years	67	18-40 years of age	13	Physical disability	6
5 to 15 years	29	41-60 years of age	33	Blind	1
Up to 5 years	4	61-80 years of age	10	Deaf	3
				Microcephaly	1
				Light "mental retardation" ⁹⁵	7
				Moderate "mental retardation"	19
				Severe "mental retardation"	27
				Multiple disorders	6

*multiple answer

Since 2006-2007, there has been a rapid change in the number of residents at SISH, with a total of 70 residents being displaced from the institution for various reasons. Most of them were transferred to community-based homes (38 residents), nine were placed in other institutions (Homes for the Elderly), and twenty-two residents have since passed away. In just one case, a resident returned to his biological family. In 2006, another person from a children's community-based home began living on her own.⁹⁶ Despite the ongoing policy of not accepting new residents at the SISH, during the last five years there were three new admissions.⁹⁷

SISH, number of residents since 2007

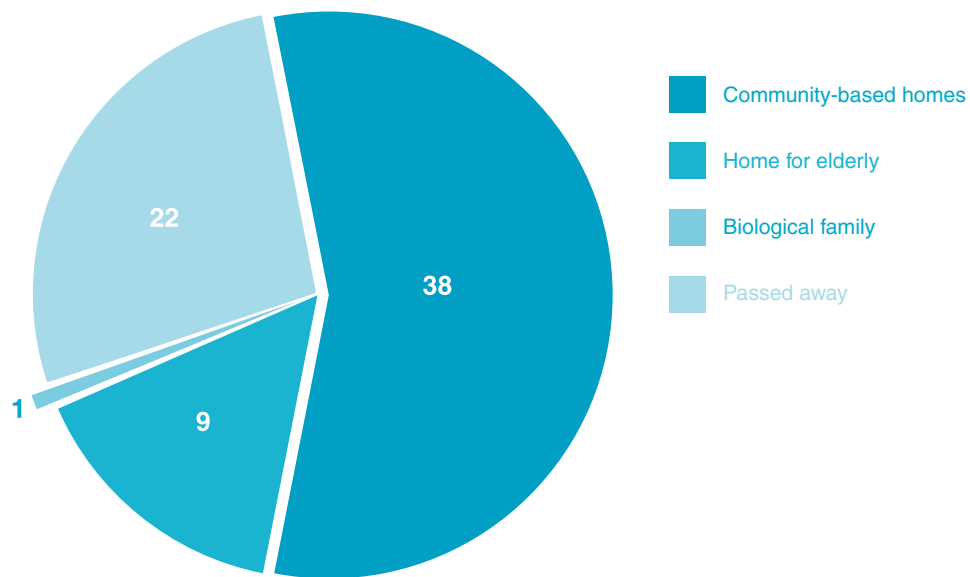


⁹⁵ Most legal terminology that refers to persons with disabilities, especially to persons with psychosocial or intellectual disabilities, is archaic and politically incorrect. In most cases, the authors have replaced such language with non-stigmatising terminology. In other cases, the outdated terminology is placed in quotation marks.

⁹⁶ Interview with Mrs. Biljana Stanojevic, Manager of the Children's Community-Based House.

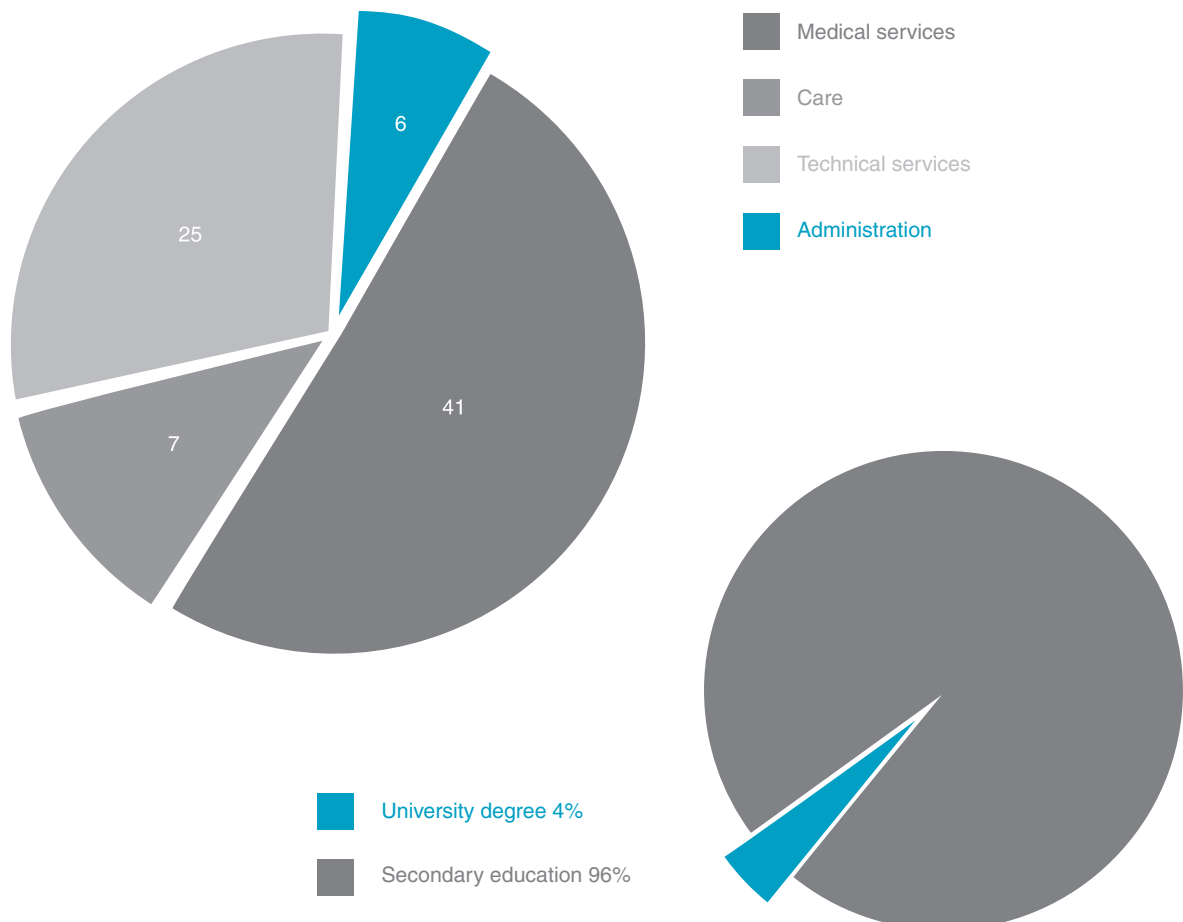
⁹⁷ Interview with Mr. Berat Zhinipotoku, the Director of SISH.

Transfer of SISH residents



SISH also has the most employees – a total of 79 – involved in providing residential care. Most employees work in health services, followed by technical services. The smallest group are employed in care and administration. Four of the 79 employees have a university degree; the rest have secondary education. Health services are provided by two general practitioners, two psychiatrists, two dentists and a laboratory technician. Vocational training is organized by the educational unit, which consists of one social worker, one professional therapist and five professional instructors.

Staff at SISH



Restrictive Measures & Monitoring Mechanisms

The only daily activity at SISH is drawing. The institution has a series of corrective measures that can be applied when a resident misbehaves, including changing their bedroom, discussing the issue with the resident, and – in cases of a serious breach of house rules – referring the matter to the Disciplinary Commission. In cases of aggression (or self-mutilation), tranquillisers are used. Other forms of restrictions recorded during visits to community-based homes include prohibiting or limiting the time spent walking outside, or restricting cigarette use.

There is no clear indication as to how informed the residents are regarding their rights and responsibilities, since no studies have been conducted to tackle this issue in more detail. The officials in charge of these institutions explain that all necessary communication is conveyed to those residents capable of understanding what they are told. For those who have difficulties with verbal communication, the guardian is informed instead (which implies that residents incapable of understanding have had their legal capacity removed and thus have a guardian). We have no evidence regarding any complaints on the part of residents regarding their treatment, or a breach of their rights. The document regulating SISH's internal work envisions a mechanism for dealing with residents' violation of house rules, but it says nothing about mechanisms for residents to file complaints.⁹⁸ According to officials from SISH and the community-based homes, the Ministry of Labour and Social Welfare conducts regular visits, but the inspection procedure is vague and a mere formality: inspections are neither standardized nor consistent.

The document governing the work of the SISH states that residents who are “prone to drinking alcohol, gambling, or have other problems can go out to the city only when accompanied by an escort who will correct his or her behaviour, and upon written permission from the social service officer.”⁹⁹ The SISH rules further state that all city visits must be checked with the social service officer. Unannounced departures are treated as an escape from the institution.¹⁰⁰ The rules do not go into any detail regarding the measures for restraining the residents, apart from stating that all residents who have been prescribed a particular medication must take this medication.

Field observations show that the staff's communication with and treatment of residents falls far short of being satisfactory. On more than one occasion, the staff used force to physically remove residents who were not obeying staff requests to leave the premise. Staff members also used inappropriate language when discussing people with disabilities. Communications or encounters with residents are impersonal and inconsiderate. The monitoring teams recorded several instances of residents with signs of bruises of uncertain origin on their body and face. On several occasions, the monitoring teams witnessed employees using physical force to drag out residents who were reluctant to leave the premises. Some facilities remain inaccessible to wheelchair users; most importantly, bathrooms are not properly designed and lack the necessary adaptations for wheelchair users.

The monitoring visits also assessed the institutions' physical conditions. Most residents' rooms have old (and often only the most basic) furniture: a bed and a dresser for the resident's clothes. The residents' clothes are often dirty, the wrong size, and worn. At SISH, all belongings, including personal hygiene items, are placed kept by the staff, and residents must ask for them if they want to use them. The monitoring teams also encountered a heavy odour at the Shtime Special Institute and at the community-based homes, coming from excessive detergent or other cleaning products, or from accumulated garbage that was not properly disposed of.

Residents at SISH and the community-based homes have few opportunities for pursuing a sense of privacy. The residents could not personalize their bedrooms, nor could they close their bedroom door as the door handles were missing. At SISH, all personal items are kept separately by the staff, meaning that residents cannot develop any sense of personal belongings in order to preserve their identity.

⁹⁸ The document does recognize the rights that the residents are entitled to according to the relevant laws and sub-legal acts, as well as the right of residents to be protected against any form of abuse that is considered a breach of human rights.

⁹⁹ Regulation on Internal Organization of Work of the Special Institute in Shtime, No. 08/2006, Article 16, Ministry of Labour and Social Welfare.

¹⁰⁰ Ibid., Article 49.

We did not obtain any information on the funding allocated for community-based homes from any primary source. Our interviews with the officials in charge of managing these institutions did not yield any information regarding the available funds. The 2009-2011 National Action Plan for People with Disabilities in Kosovo states that the operational cost of community-based homes is more than 200,000 euros per year.¹⁰¹ This amount also includes buildings maintenance and all other expenses pertaining to the homes' operation. The funds were allocated through the Ministry of Labour and Social Welfare. Each year, plans are made for the amount of funding required in the next year. Although no major renovation projects were reported during the period under review, the list of MLSW priorities for 2012 dedicates more than 0.5 million euros from the ministry budget for renovating the SHSI and senior home, as well as the construction of a community home for people with disabilities.¹⁰² Fund allocation shows that the SHSI's closure is a priority for the Kosovo government, and that the MLSW is still not ready to consider new approaches to the provision of community-based services for people with intellectual disabilities, but is continuing to follow strategies that have segregated people with intellectual disabilities from the rest of society.

Considering the number of residents in community-based homes, the yearly cost for a single resident is estimated at nearly 2,000 euros per year.

Community-based services

In addition to introducing socially oriented treatment for people with psychosocial disabilities, another aspect of the modernising the system involves building capacities for multi-disciplinary treatment and prevention. In 2004, the first community-based mental health facility was built in Prishtina/Pristina. Over the following years, a similar centre was built in each regional centre, and staff was recruited. To date, a total of seven¹⁰³ community-based mental health facilities have been opened for providing services to people with psychosocial disabilities and illnesses.¹⁰⁴

Community-based mental health facilities operate under the aegis of the Ministry of Health. As noted above, each region has a functional administrative unit, and each unit consists of a Community Home for Integration, a Community-Based Mental Health Centre, and a Mental Health Centre for Children and Adolescents. In addition to these complementary multi-disciplinary services, another identified need for increasing capacity for independent living within a community setting are workshops aimed at developing marketable skills. Therefore, as part of its services for persons with mental disabilities, the Ministry of Labour and Social Welfare has also built a network of community-based homes and offers shelter to people with intellectual disabilities. The two ministries cooperate in establishing resources and providing services to meet community needs. However, in some instances the roles and responsibilities are not being faithfully met. Following the reorganization of the Shtime Special Institute in 2006 and the introduction of a more comprehensive vision of mental healthcare as outlined in the 2008-2013 Mental Health Strategy in Kosovo, the Centre for Integration and Rehabilitation of Patients with Chronic Psychiatric Illnesses in Shtime was established. This step goes in hand with the process of de-institutionalisation. It promotes the categorisation of clients by type of disability, helps to provide services to institutionalised people with disabilities, and encourages the responsible stakeholders to provide these services. This institution is managed by the Ministry of Health, although some residents have intellectual disabilities. To date, the institution has not yet established its legal status, has not approved statutes that might serve as a governing framework for the institution, and offers medical treatment and shelter predominantly to ex-residents of the Shtime Special Institute.¹⁰⁵

¹⁰¹ First report on implementation of National Activity Plan for People with Disabilities in Kosovo 2009-2011, Office for Good Governance, Prime Minister's Office.

¹⁰² The Ministry has allocated significant funds for 2012 for the renovation and construction of new facilities: 200,000 for the renovation of SISH and community-based homes, and 0.5 million euros for the construction of a new social care facility in Viti/Vitina. As of the writing of this report, work on these projects has yet to commence.

¹⁰³ Administrative Guideline 07/2009 (in health) for professional services of mental health in the Republic of Kosovo, Article 2, Ministry of Health.

¹⁰⁴ Ibid., Article 3.

¹⁰⁵ Interview with Mr. Ajet Bunjaku, Director of the Integration Centre in Shtime.

Community-based homes

Community-based homes have been established in order to help people with disabilities engage in independent community living.¹⁰⁶ Over the years, these houses have also served as intermediary facilities for housing people with disabilities, primarily SISH residents following de-institutionalisation and before reintegration into an independent community living environment. The three types of community-based homes offer services to children, adults and the elderly with intellectual disabilities. Five community-based homes offer services to residents between the ages 18 to 65, whereas children and the elderly are accommodated in two separate community homes.¹⁰⁷ Community-based homes have been built progressively since 2001, based on a similar architectural design and with a capacity of 10 residents.¹⁰⁸ Currently, a total of 70 residents are placed in community-based homes, 38 of whom were transferred from SISH and the remaining are new enrolments. Residents usually live in double rooms. All houses have common areas such as a day area, kitchen, eating room, and bathrooms.

In several instances, neither the facility's capacity nor the residents' age were respected.¹⁰⁹ For example, the community-based homes for children have residents over the age of 18. Also, field visits found that the community-based homes in Decan/Decane and in Gracanice/Gracanica were built in a remote area, on the top of a hill on the outskirts of the city. The facilities' placement in such distant location represents a barrier for residents in engaging actively in community living, receiving all the necessary services, and pursuing an independent and fulfilling life.

The community-based homes usually have between eight and eleven employees. As with the Shtime Institute, the community-based homes rarely employ university-trained professionals. Most staff have completed secondary school, predominantly in the field of medicine. Out of the five community-based homes visited, only one employs a psychologist.

According to reports, most institutions providing mental health services lack protocols, i.e. standard procedures regarding how service providers should respond to particular events and occurrences.¹¹⁰ A similar situation dominates other institutions providing services for people with intellectual disabilities as well. The Ministry of Labour and Social Welfare's regulation for the internal organization of work at the Special Institute in Shtime remains the most detailed guideline for this institution to date.¹¹¹ This document includes general guidelines relevant to life at and work in this institution. We should point out that the tone of the instructions does not evoke an empowering, result- and resident-oriented environment.

The managers of community-based homes have reported that they organize field trips for their residents. These trips involve visits to a park, picnics, going out into nature, and other trips of this kind. Most field trips go out into nature, where there are limited encounters with the large community. None of the community-based homes we visited presented any planned activities for the upcoming period, and it is not clear whether the institutions have any sort of yearly calendar of events. Reportedly, interaction with the public at large is sporadic as well. In addition, the community-based homes have not developed any strategies or joint activities that might enhance communication between communities, and the fact that they function in a closed manner can be seen as the main factor contributing to the general population's lack of interest and willingness in communicating and socializing with the residents. Only one manager of a community home reported having organized visits to the community home by the youth living in that city.

¹⁰⁶ Role of Division for Institutional Care, Department of Social Welfare, Ministry of Labour and Social Welfare.

¹⁰⁷ Interview with Mrs. Raza Aliqkaj, Director of House for Elderly in Prishtine/Pristina. Skenderaj/Srbica and Gurakoc/Gurakovac have community-based homes for placement of elderly; Shtime/Stimlje, Ferizaj/Urosevac, Vushtrri/Vucitrn, Kamenice/Kamenica and Decan/Decani for adults; and, Gracanice/Gracanica and Shtime/Stimlje have community-based homes for children.

¹⁰⁸ Community-based homes for the elderly have been planned to house 20 residents each.

¹⁰⁹ Field visits by the research team took place between August and October, 2011.

¹¹⁰ Mental Health Strategy in Kosovo 2008-2013, Ministry of Health.

¹¹¹ Regulation No. 08/2008 for internal organization of work in the Special Institute in Shtime (SISH), Ministry of Labour and Social Welfare.

Planning and Strategy for De-institutionalisation

As the MLSW manages the Special Institute in Shtime, this ministry is also accountable for the process of de-institutionalisation. Although the process of de-institutionalisation was begun many years ago, the process is seriously behind in implementing a functioning alternative system. The deadlines for closing the Special Institute in Shtime have been postponed several times. Most recently, the facility was supposed to be shut during 2011. Despite the goal of SISH residents living independently and becoming socially integrated into their communities, this objective has been achieved in only a few cases. One of the most successful aspects of the de-institutionalisation process reported by the MLSW is the placement of SISH residents into community-based homes. However, the transferred residents remain in the community-based homes for an unspecified period of time and have only vague prospects for leading an independent life and becoming socially integrated.

Another obstacle to de-institutionalisation is the fact that the Special Institute in Shtime has been accepting new residents. The official no-acceptance policy has been ignored, new enrolments have been accepted and may be accepted in the future. New enrolments are possible only in very specific circumstances, and each individual case should be reviewed by a commission established solely for this purpose. The members of this commission include an official from the Division for Institutional Care responsible for persons with mental disabilities,¹¹² a social worker, and a doctor from the Special Institute in Shtime.

Non-Governmental Organizations' Contribution to the Process of De-institutionalisation

In 2007 the international organization Mental Disability Rights International (MDRI) was invited by Kosovo institutions to develop a plan¹¹³ for implementing the process of de-institutionalising the SISH residents. This organization – today known under as Disability Rights International (DRI) – is dedicated to promoting the rights of people with disabilities around the world.¹¹⁴ Based on this plan, DRI has analysed modalities of transition to communities and developed community-based services for residents of SISH and the Shtime Integration Centre. These efforts included an examination of the possibilities of replacing institutionalisation with alternative accommodations. One particular objective of the study was to propose a model that would make it possible to accommodate people with mental disabilities in a community setting, in harmony the aim of including them in community life and integrating them into the general social, political and economic life of their respective communities. This alternative would have to be a community-based solution through which the institutes' residents could integrate into community life and be empowered to exercise their right make decisions relating to their personal lives.

The MDRI team explored several scenarios from other countries that have successfully implemented de-institutionalisation and that offer examples of best practice. Moreover, by offering a model that could potentially achieve positive results, Kosovo was seen as a potential role model for other countries in the region that will be facing the same issue in the future.

With the aim of implementing a community integration model that would promote residents' independence and self-determination at a feasible level of implementation costs, the MDRI team proposed moving residents into small groups that would live independently in private homes within the community. Another option was for families to accept the residents into their homes. In return they would receive financial compensation in the form of rent. The financial feasibility study showed that these proposed models would not add any additional financial burden onto the ministry's budget, since the funds allocated for operating the SISH would be enough to pay for either of the two proposed scenarios. None of the two suggested models was implemented by the Kosovo government. The government claims that the de-institutionalisation process was not completed because of its high

¹¹² Operating under the Department of Social Welfare, Ministry of Work and Social Welfare.

¹¹³ Kosovo Model: The Plan for Protection of Rights and Inclusion of People with Intellectual Disabilities, Mental Disability Rights International, 2007.

¹¹⁴ For additional information about the scope of work of this organization, visit www.disabilityrightsintl.org.

budgetary cost, stating that “once the funds are available, the last residents from Shtime Special Institute will be transferred into the community and de-institutionalisation will be completed at last.”¹¹⁵

Administrative Grounds for New Enrolments at SISH

The administrative guidelines for new enrolments at SISH and community-based homes contain controversial and contradictory instructions as pertains to the further functioning of the Special Institute in Shtime. Although the guidelines confirm the MLSW commitment to the SISH’s de-institutionalisation,¹¹⁶ they also contain enrolment criteria for further placements within this institution.¹¹⁷ Since there are only few examples of the reintegration of persons with intellectual disabilities into the community, approval of these guidelines calls into doubt the ministry’s true commitment to finally closing the SISH and enforcing the policy of not accepting new enrolments at this institution.

Homes for the Elderly

The Ministry of Labour and Social Welfare also manages residential facilities for elderly people without family care. There are currently three institutions for housing elderly people.¹¹⁸ Placement in these homes is open to residents of Kosovo aged 65 years or older and who have no family care – i.e., no relatives who can look after them.¹¹⁹ These three facilities are home to a total of 110 people, nine of whom have intellectual disabilities.¹²⁰ The criteria for placement include that the applicant be in a good mental state and free from infectious diseases.¹²¹ The definition of *good mental state* is not further explained; excluding people on the basis of their mental condition would be discriminatory.

Provision of Medical Care to Residents of the SISH and Community Homes

Medical care for the residents of the SISH and community-based homes is provided by the Shtime Institute’s in-house doctors. Depending on the circumstances, more specialized treatment is provided at the Prishtina/Prishtina central hospital. All residents have a personal health card on which details regarding their current treatment and health history is recorded. Almost all residents of the SISH and community-based homes have been diagnosed with intellectual disabilities, varying in degree from mild to severe. There is no information whether the inspections performed by the ministry include any quality control of the residents’ medical care and type of diagnosis.

Reintegration into the Community – A Path with Many Challenges

Considering that only one resident has been returned to his biological family, we can safely state that residents’ rehabilitation has not had any significantly positive results. We have no further information on whether this one example of community reintegration and independent living succeeded, and none of the other residents have been reintegrated into the community. The officials whom we contacted did not anticipate any progress in the current institutional residents’ rehabilitation process, and are pessimistic as to the possibility of achieving any positive results with the population they work with. Other respondents pointed out that the staff at these institutions does not have the proper qualifications, and that further training is very much needed.

¹¹⁵ First evaluation report on implementation of National Disability Action Plan for People with Disabilities in Kosovo, Office for Good Governance, Prime Minister’s Office.

¹¹⁶ Administrative Guideline No. 06/2011 for work and placement of residents, persons with mental disabilities – delay in mental development at the Special Institute in Shtime and in homes with community based, Article 8.2, Ministry of Labour and Social Welfare.

¹¹⁷ Ibid., Article 6.

¹¹⁸ In Prishtine/Prishtina, Istog/Istok (Gurakoc village) and Skenderaj/Srbica.

¹¹⁹ Administrative Guideline 07/2011 for activities and requirements for accommodating the residents of community-based homes, homes for the elderly, and homes for people without family care, Ministry of Labour and Social Welfare.

¹²⁰ Activities of the Ministry of Work and Social Welfare for 2010, Ministry of Labour and Social Welfare, and interview with the Director of the Home for Elderly in Prishtina/Prishtina.

¹²¹ Administrative Guideline 07/2011 for activities and requirements for accommodating the residents of community-based homes, homes for the elderly, and homes for people without family care, Article 6, Ministry of Labour and Social Welfare.

Social Assistance on the Grounds of Disability

Existing legislation provides disability benefits for people with disabilities who are eligible to pursue this right. Disability benefits are regulated by two laws: one for the adult population¹²² and one for children.¹²³ Disability benefits for children with permanent disabilities cannot move independently or perform daily activities are paid to their caretakers.¹²⁴ Children with disabilities defined as children who are a) immobile, b) totally blind, or c) have a permanent illness that prevents them from moving independently, with or without aids, or who are not able to feed themselves, dress or undress, to carry out their physiological needs and maintain the necessary personal hygiene.¹²⁵ All residents of Kosovo are eligible, provided that they are a caretaker for a child younger than 18 years of age with a permanent disability. The initial application is reviewed by the Centre for Social Work, which consults an expert evaluation committee for each application.¹²⁶ The evaluation committee consists of five members, most of whom are medical experts (one member is a social welfare officer, and another member can be an expert on social sciences). The aim of the committee is to “examine the type, level and severity of the physical, mental and sensory impairment of permanent disabled children.”¹²⁷ Data from mid-2011 reveal that a total of 2,354 caretakers are listed as beneficiaries of children’s disability benefits in the amount of 100 euros a month.

Disability pensions are provided to the adult population aged 18 to 65 if a medical diagnosis of the person’s physical, sensory and mental state determines that the presence of an illness or disability that prevents the applicant from performing any paid work. The data from mid-2011 reveal that a total of 18,021 beneficiaries receive a disability pension.¹²⁸ The law provides for other forms of assistance and supportive measures for “permanent and utterly disabled persons,” including free public transportation, special seats for disabled persons on public transportation, half-price tickets to cultural and entertainment events, access to public buildings, and an exemption from customs fees for equipment that may facilitate their independent living.¹²⁹

Non-Governmental Organizations’ Support for People with Intellectual Disabilities

The existing support services in the community are offered mainly by non-governmental organizations established by grassroots civic associations or by communities of people affected by a particular disability. Since 1999, international donors have significantly helped the non-governmental sector in terms of organizational improvements and taking a more systematic approach to dealing with community issues. Over the past decade, donations have been used to establish non-governmental organizations for tackling various issues, including disabilities. Over the years, however, donations have declined, and most of these services now rely on public funding from existing government funds (on the local as well as national levels) for the support of non-governmental organizations or for people with disabilities. This funding is quite minimal, however, and is just enough for these organizations to engage in a limited number of activities but is not sufficient for continuous operations. There has been a slight increase in the number of organizations that have been successful in acquiring funding from private companies. These non-governmental organizations have shown considerable success in acquiring financing from the private sector and recruiting volunteers to help in their operations.

Numerous local non-governmental organizations that have implemented projects in the fields of disabilities and human rights have benefited from donations from the European Union’s EIDHR Program, including K-MDRI, Handikos, Down Syndrome Kosova, and Handikos Kosova. Funding for

¹²² Official Gazette of the Republic of Kosovo, No. 21/08, Law on Disability Pensions in Kosovo, No. 2003/23.

¹²³ Official Gazette of the Republic of Kosovo, No. 37/08, Law for Material Support for Families of Children with Permanent Disabilities, No. 03/L-022.

¹²⁴ Ibid., Article 5.

¹²⁵ Ibid., Article 6.

¹²⁶ Ibid., Article 12.1.

¹²⁷ Ibid., Article 7.

¹²⁸ Disability Scheme in Kosovo, Ministry of Labour and Social Welfare. Accessed 23 February 2012. <http://www.scribd.com/doc/57108265/Regional-Meeting-on-Disability-Pension-in-Kosovo>.

¹²⁹ Official Gazette of the Republic of Kosovo, No. 37/08, Law for Material Support for Families of Children with Permanent Disabilities, No. 03/L-022, Article 13.

the NGOs involved in issues related to people with disabilities is usually on short-term project basis, ranging from several hundred to several thousand euros. Most of these projects involve study visits, information campaigns, advocacy projects, sports tournaments, and the like.

In 2003, Disability Rights International (DRI) and the Kosovo Mental Disability Rights Initiative (K-MDRI) joined forces to establish Ne per Ne (We for Ourselves), the first and only local non-governmental organization by and for people with intellectual disabilities. The organization's founders are self-advocates with intellectual disabilities. The organization's main goal is to promote the human rights of people with intellectual disabilities by urging Kosovo's policymakers to reform policies and existing laws in accordance with international human rights standards. We for Ourselves have proven to be a valuable asset for its members, a place where they can participate in workshops and panel discussions and attend peer-support group meetings or workshops on self-advocacy and life skills. The organization has been recognized for its support for people with intellectual disabilities, and for providing people with intellectual disabilities the opportunity to network and to develop the skills for engaging in independent community life, realizing their self-advocacy skills, and taking part in decisions affecting their lives.

A letter from a Ne per Ne advocate from Peja/Pec

As a self advocate, I need to show greater interest towards persons with disabilities and to make sure that no violence is being exercised upon them, that they are not mistreated by their families and are not kept locked up, but can go out freely, invite new members to the meetings, come and have some coffee, walk around, talk about various subjects, etc. In terms of integrating disabled persons into society, I believe that society should respect persons with disabilities and not use bad words towards them. Families should go out with their children, because if the family supports and fights for the rights of their children then society will support them as well.

My advice for all people who prevent us from living a better life:

- Do more about the employment of people with disabilities,
- We all should have a chance to a proper education, and
- Do not call us “stupid” or “sick” – if were really sick, then we would go to the hospital and get treatment.

Conclusion

Although most care for disabled people is organized through a network of community-based services that have been tailored to meet their needs through the cooperative effort of multiple stakeholders, research has shown that institutional care continues to play a dominant role in the care that is offered to people with intellectual disabilities.

For several years now, Kosovo's government has pledged to complete the process of de-institutionalisation by moving residents out of the Special Institute in Shtime. Nevertheless, the SISH continues to operate with no visible signs of activities that might lead to its closure in the near future. What is more, despite the current policy of no longer admitting resident to the SISH, there have been new enrolments over the past five years. In 2011, the Ministry of Labour and Social Welfare approved an administrative guideline describing the criteria for new enrolments.

Part of the de-institutionalisation process was to transfer SISH residents to community-based homes designed to facilitate the independent living and community reintegration of people with disabilities. Field observations have found that the residents of these community-based homes are not directly engaged in social and community life, and that they are not being helped towards independent living. Instead, they are directly supervised, with few chances for community integration in the future. The homes' residents have few prospects for the future, since their way of life is quite similar to the way they had lived at the SISH. In fact several “community-based homes” are not community-based at all: These were built far from residential neighbourhoods, with little or no opportunities for social interaction or community life. Access to these homes remains centralized, and visits must be approved by

the Ministry of Labour and Social Welfare, thus restricting the residents' possibilities for contact with the outside world. Finally, the staff at these homes have demonstrated a lack of compassion and dedication to preserving the residents' rights and dignity.

Since the de-institutionalisation plan does not provide any clear strategy on how to integrate SISH residents into the regular community, the most crucial part of the de-institutionalisation process – the closing of SISH in 2011 – remains unfulfilled. Despite the existence of a de-institutionalisation plan produced specifically for the SISH by Disability Rights International, Kosovo's government has not publicly discussed whether it will implement or abandon this plan, and has offered no viable alternatives. What is more, the available data show an extremely low rate of re-integration and social inclusion, and there is little hope for the successful transition from institutional care towards social inclusion.

People with disabilities face numerous hurdles to their integration into community life. Governmental institutions have failed to promote the concept of community service and to extend institutions' operations into the local community by engaging the general public and building a sense of trust and cooperation. Non-governmental organizations are struggling to consolidate their operations, face financial constraints and insecurities, and often operate only at a few locations around the country.

Recommendations

The government needs to become more involved in applying existing laws and policies with the aim of promoting independent living in a community setting. It must reaffirm its commitment by producing action-oriented strategies and building the capacities necessary for fully promoting independent community-based living.

In order for people with disabilities to be able to pursue independent living and to become integrated into their communities, the social care system needs to shift the balance away from service providers working with a medical model towards increased socio- and psycho-therapeutic treatment.

The government must follow through on its pledge to close the Special Institute in Shtime by presenting a realistic timeframe for doing so. The Ministry of Labour and Social Welfare should consider reallocating available funds currently budgeted for renovating the SISH and community-based homes and the construction of new community homes, and should instead explore new inclusive approaches for ensuring that people with intellectual disabilities are fully integrated into the community and are no longer isolated and segregated. The planning process should be public, with input from civil society, including residents and organizations for people with disabilities, who must be viewed as crucial and indispensable stakeholders in this process.

The aim of the de-institutionalisation process must be to integrate all current SISH residents in community life. Promoting residents' independence and right to self-determination should be a priority goal, and their integration must be physical within the community. The option of placing residents into small groups living independently in private homes within the communities should be considered as a foundation for possible further modification. All residents must have the chance to participate in developing their plan for future placement.

Policymakers and anyone engaged in working directly with people with intellectual disabilities must immediately be provided with ongoing workshops on human rights and disabilities. Ethical and professional conduct must be clearly defined and respected at all times. All breaches of an institution's rules must be disciplined in a proportional manner. Monitoring visits organized by the government should be closely supervised (preferably through the inclusion of independent bodies and/or members). This requires the creation of objective monitoring mechanisms and truthful reporting on treatment, as well as a review of key indicators related to the preservation and promotion of all residents' human rights.

The government should be supported in its efforts at establishing and increasing the number and quality of community-based services involved in promoting independent community living. Further chances are needed in order to improve capacities for recruiting community resources in order to protect people's independence, respecting their physical, mental, social and professional capabilities, and ensuring their inclusion and participation in all aspects of life.

EDUCATION

Legal and Policy Analysis

Education legislation in Kosovo makes primary school mandatory for all school-aged children. The country's constitution grants all children the right to free basic education.¹³⁰ Moreover, the constitution also requires public institutions to ensure that everyone has equal access to education in accordance with their needs and abilities.¹³¹ The right to free education and the need to create the conditions necessary to accommodate students' educational needs leads to the need to pass additional laws in order to make this policy of all-inclusive education possible for all of the country's children.

A recently passed law regulating pre-university education¹³² reorganized primary and secondary education in harmony with the levels defined by the International Standard Classification of Education (ISCED), which was compiled in order to facilitate the reporting of education-related data on the national and international levels.¹³³ The Law on Pre-University Education also includes the option of alternative forms of schooling if the child does not successfully complete the ninth by the age of 15. Failure to enrol children in primary education is considered a violation of the law, and disciplinary measures are foreseen for offenders – ranging from disciplinary fees to criminal charges.¹³⁴ It remains the sole responsibility of the parent to enrol their children and supervise their regular attendance during the time that they must attend compulsory education. This means that any disciplinary measures resulting from a child not being enrolled in school are applied towards the parent. The school authorities or local government are accountable for a child's school enrolment, which results in a lack of motivation on the part of local authorities to recruit and engage community resources in order to increase school enrolment and make sure that all eligible children attend school. Under this law, the parent responsibilities are not extended to a guardian. The new Law on Pre-University Education foresees that, depending on the available budget, by the 2015/2016 academic year, mandatory education will be expanded up to the secondary level, i.e., until a child finishes secondary school.¹³⁵ The Law on Primary and Secondary Education enforces regular school attendance (as opposed to mere enrolment) by providing for consequences to the parents of children who do not attend classes at a satisfactory level.

Changes contained in the new Law on Pre-University Education

The new Law on Pre-University Education introduces two important new concepts. The first relates to the possibility of pursuing alternative education instead of formal schooling. The law requires parents to present the municipal authorities with arguments to justify home-schooling the child or sending it to another appropriate form of full-time education suitable to the child's age, abilities and any other special needs the child may have.¹³⁶ Furthermore, home schooling is subject to inspections by the Ministry of Education and must be authorized by the ministry following consultations with the municipal authorities.¹³⁷ This provision of the law may open the way to community-based programs in which children with disabilities attend informal education organized by various groups, including

¹³⁰ Constitution of the Republic of Kosovo, Article 47.

¹³¹ Ibid., Article 47.

¹³² The Law on Pre-University Education No. 04/L-032 (Official Gazette of the Republic of Kosovo, No. 14/11) entered into force on 15 September, 2011. It overrides the previous law on primary and secondary education from 2002. Since it was passed only recently, and because some arrangements still need to be taken for the proposed changes to be implemented, this section reviewed the old law. The changes to special education planned in the new law are discussed as well.

¹³³ Based on this division, mandatory education starts with the attendance and completion of level 1 and 2, phase one and two of basic (primary) education. Education until the completion of level 2 (as per ISCED) or the equivalent (up to grade nine) is considered obligatory for all Kosovo citizens.

¹³⁴ Official Gazette of the Republic of Kosovo, No. 8/06, Law on Primary and Secondary Education, No. 2002/2, Article 7.14 and 7.15.

¹³⁵ Ibid.

¹³⁶ Ibid., Article 47.

¹³⁷ Ibid.

non-governmental organizations. It may also provide opportunities for the development of educational materials for children with disabilities that can be taught by the parents. Possible downsides are the quality of education in such programs, a lack of social contact with peers, and poorly developed social skills. In addition, this form of schooling may be used by the authorities to manipulate the data regarding the number of children enrolled in some form of education. Moreover, home schooling may be silently approved as a standard form of education for disabled children, and school authorities may suggest it as the first alternative to regular schooling in order to avoid having to teach children with disabilities.

The second new concept contained in the Law on Pre-University Education involves inclusive education. This provision of the law reiterates the need for educational or vocational institutions to accommodate all children and to promote the integration of and contact among children. Support for children must be based on their intellectual needs. Parents are encouraged to enrol their children in regular schools, with special schools or resource centres¹³⁸ serving as an alternative choice only if an expert evaluation has determined that the child will not benefit from being enrolled in regular classes. All municipality must establish a professional evaluation team to act as a support mechanism for special education. The evaluation team should consist of an education specialist, social workers, a psychologist, and rehabilitation professionals, and its objective is to provide external support, counselling and advice for teachers and parents. If a parent asks, the team may also recommend teaching techniques, teaching tools and other options in order to improve the child's performance and well-being.

Aspiring towards inclusive education

The approach to inclusive education established with the UNMIK administration in Kosovo introduced the notion of attached classes. Attached classes are part of regular schools, and are a place where children with disabilities received education while using the same premises as other children. The children shared the same buildings and other school facilities, except that the children with disabilities were brought together within one classroom. With time, such attached classes were established throughout the country, and now each municipality has at least two attached classes.¹³⁹ The aim of attached classes was to accommodate children with mild impairments, and to serve as a transitional stage until the implementation of inclusive education in which children with disabilities would be enrolled in regular classes.

From the earliest days of the new approach, many children with mild forms of disabilities (including mild intellectual disabilities) were enrolled in these classes. Disabled children could also choose to attend one of the country's seven special schools.¹⁴⁰ Because of the versatility of the auxiliary teaching tools at special schools and the better qualification of the teaching staff, children with mild or severe forms of disabilities were more often enrolled in special schools. With the reorganization of the education system aimed at providing more appropriate support for children with disabilities, special schools are now being transformed into resource centres.¹⁴¹ The staff at these resource centres will act in the capacity of travelling teachers, and will help teachers at regular schools improve their skills for working with disabled children.

In order to promote the inclusion of disabled children into the educational process, the law requires parents, children, and school personnel to participate in reporting on the need for special education. The law requires consultations with children in order to determine whether they should participate in special education. A professional examination of the child's needs and abilities is required before enrolling a child in special education. Nevertheless, these evaluations are often subjective and are based more on the attitude and prejudices of the evaluators than on scientific facts. Professional

¹³⁸ Resource centres, special schools and units that provide special education have been described in the law on pre-university education as "[institutions that] offer special education for children with severe or multiple disabilities or learning difficulties, who are assessed as being unable to be educated in municipal schools or public training institutions."

¹³⁹ Statistics on Education 2010/2011, Ministry of Education, Science and Technology.

¹⁴⁰ The country has seven special schools for children with intellectual disabilities, one for children who are hard of hearing or deaf, and one for visually-impaired or blind children. The special schools are located in Mitrovica/Mitrovica (one in the south and the other in the north), Peje/Pec, Prishtine/Pristina, Prizren and Shtime/Stimlje.

¹⁴¹ See for example Transition from Special Schools to Resource Centre, Ministry of Education, Science and Technology/FSDEK-II, 2004.

examinations are not uniform throughout the country, and no government policy or guideline exists for defining the procedure or the tests used to decide on a child's enrolment in regular or special education.

Since the country's educational system is based on a policy of all-inclusive classes for all children, the first step is to determine whether a child will benefit from attending regular classes.¹⁴² Although the practice of all-inclusive classrooms offers many benefits, many challenges need to be seriously addressed. For instance, there is a shortage of qualified teachers capable of working with disabled children and many teachers are not motivated because their overcrowded classrooms leave little time for individual work with special-needs children.¹⁴³ Another issue is the children's stigmatisation by their peers. It is thus imperative that we consider additional measures for improving the situation of inclusive education.

The objective of Kosovo's education system is to include all children with disabilities in regular classes by a) accommodating all children, regardless of their physical, intellectual, social or other condition and by promoting integration and contact among children, b) offering relevant support on the basis of students' individual needs, and c) suggesting separate educational settings or special schools only if an expert has determined that enrolment in a regular school or training institution is impractical.¹⁴⁴ The objective of an all-inclusive educational system has been a common and fundamental goal since the start of the reform of the country's educational system with the advent of the UNMIK administration.

Special Education

Support for special education is regulated by the Law on Primary and Secondary Education, according to which it is the duty of local government (i.e., the school district) to ensure appropriate education for children who do not or cannot receive satisfactory benefits from regular education.¹⁴⁵ Parents or students may approach the municipal authorities with a request to attend special education.¹⁴⁶ Teachers are responsible for notifying the school's director if a student requires special education.¹⁴⁷ Requests for special education received from a parent or child are subject to an evaluation by a team of experts. This evaluation helps the municipal authorities reach a decision on whether the applicant can be enrolled in special education.¹⁴⁸ According to a 2007 administrative guideline, the child's placement in special education is decided by the evaluation commission, which also considers "financial constraints and budget limitations."¹⁴⁹ The professional evaluation is performed with the aim of considering whether the child can benefit from regular schooling. The evaluation identifies the child's learning difficulties and other pertinent conditions that might influence the ability to learn, determines the educational objectives that the student can be realistically expected to fulfil, decides what kind of tuition is appropriate, and rules on whether the child's difficulties can be addressed within the regular educational environment.¹⁵⁰ Each student enrolled in special education receives an individual education plan. This plan defines the student's specific educational objectives and curriculum, and describes how the information will be presented.¹⁵¹ The Ministry of Education, Science and Technology (MEST) is responsible for providing the services necessary for meeting the needs of children with disabilities.¹⁵² In addition, MEST is also responsible for providing special education services to people who have been deprived of liberty, inmates at psychiatric wards or people who are hospitalised for extended periods of time.¹⁵³

¹⁴² Law on Primary and Secondary Education, Article 37.

¹⁴³ Interview with Mrs. Luljeta Kabashi, Special Education Official, Ministry of Education, Science and Technology.

¹⁴⁴ Law on Pre-University Education, Article 40.

¹⁴⁵ Law on Primary and Secondary Education, Article 35.

¹⁴⁶ *Ibid.*, Article 36.1.

¹⁴⁷ *Ibid.*, Article 36.2.

¹⁴⁸ *Ibid.*, Article 37.1.

¹⁴⁹ Administrative Guideline, No. 9/2007, Professional Assessment of Children with Special Needs, Ministry of Education, Science and Technology.

¹⁵⁰ Law on Primary and Secondary Education, Article 37.2.

¹⁵¹ *Ibid.*, Article 38.

¹⁵² *Ibid.*, Article 15.1.

¹⁵³ *Ibid.*, Article 15.2.

Individual Education Plans (IEPs)

Kosovo's education system requires every child with a disability who attends school to have an individual education plan. This plan acts as a framework for the optimal development of the student's skills within the educational process. The Law on Primary and Secondary Education also defines what the IEP must contain – specifically, it must describe educational objectives and educational content as well as the manner in which the teaching will be organized.¹⁵⁴ Consequently, the plan has a pedagogical character, enabling teachers to implement the agreed objectives and helping them to organize the teaching process. The objective is for all activities to be aimed at promoting the student's individual achievement.¹⁵⁵

According to the Law on Primary and Secondary Education, municipalities can organize safe and efficient transportation of children who attend mandatory education.¹⁵⁶ What is more, the municipal authorities cannot charge disabled children for the trip to school and back home.¹⁵⁷ Since the law does not oblige municipal authorities to ensure transportation for students, this practice has been rarely implemented.¹⁵⁸ The new Law on Pre-University Education regulates the transportation of children with disabilities more clearly. The new law requires municipal authorities to provide safe and appropriate transportation for children with disabilities who are attending school, both in regular or attached classes. It requires the Ministry of Education to organize transport or to arrange appropriate residential care for children attending special schools or resource centres. The law states that the transportation provided is subject to professional evaluation by the municipal authorities, but does not provide further details on this issue.

Improving School Enrolment

Children with intellectual disabilities have been specifically identified as a group against which discrimination is prohibited in terms of enrolment and opportunities for advancing through all levels of primary and secondary education.¹⁵⁹ However, according to a report prepared by the disability division of MEST,¹⁶⁰ this right is not being fully respected, as the government is not sufficiently engaged in creating the conditions for enrolment and advancement, especially for children with various types of disabilities.

The Ministry of Education, Science and Technology recently compiled a strategy for including all children with disabilities in the education system.¹⁶¹ This strategy establishes five objectives for the period from 2010 to 2015: (1) identify children with special education needs, provide early intervention and increase their numbers in the education system, (2) provide supporting mechanisms for all-inclusive schools, (3) professional development of educational staff, (4) improve physical infrastructure for all-inclusive schools, and (5) raise general self-awareness. One of the activities arising from this strategy that might make a difference in restructuring the education system and providing better results is the transformation of special schools into resource centres, which was set to occur by 2011. The strategy does not set a target number of children and timeline for including children with disabilities in the education system, apart from confirming that the process will continue to be a priority in the future.

¹⁵⁴ Ibid., Article 38.

¹⁵⁵ Strategic Plan for Organizing Inclusive Education of Children with Special Needs in Pre-University Education in Kosovo 2010 – 2015, Ministry of Education, Science and Technology.

¹⁵⁶ Ibid., Article 22.

¹⁵⁷ Ibid., Article 22.1.

¹⁵⁸ In a survey performed by the Kosovo Education Centre in five municipalities, between 11% and 33% of teachers report that the school provides transportation for eligible children. The report recommends further engagement of school directors in lobbying the Municipal Directorate of Education for the right to use organized transportation to school. Accessed October 2011. <http://www.kec-ks.org/document%27s/MONITORIMI%20I%20MENAXHIMIT%20TE%20FINANCIVE%20KOMUNALE%20TE%20ARSIMIT.pdf>.

¹⁵⁹ Law on Primary and Secondary Education, Article 5.

¹⁶⁰ Brochure on Identifying, Assessing and Educating Children with Special Needs, Ministry of Education, Science and Technology, 2007.

¹⁶¹ Strategy for Inclusive Education of Children with Special Needs 2010-2015, Ministry of Education, Science and Technology.

In terms of the objectives for all-inclusive education, protecting equality and respecting diversity in education, the educational strategy for pre-university education¹⁶² compiled in 2007 establishes the conditions necessary for including all children in mandatory education by 2017. Furthermore, it calls for the creation of favourable condition for including disabled children in the education system.¹⁶³ The strategy includes a commitment on the part of the MEST to cooperate with other institutions in facilitating the inclusion of disabled children at all levels of education. In view of the fact that this is the fourth year of the strategy's implementation, little progress has been made in including disabled children in the education system. Based on the current trends, it seems unlikely that this objective will be met by 2017.

Analysis of Practice

The education of children with disabilities in Kosovo is provided through opportunities to attend regular schools, attached classes or special schools. According to the Law on Primary and Secondary Education, all children have the right to attend school. However, this study has found that this right is not being fully respected.

The exact number of children with disabilities in Kosovo is not known. Based on the data most commonly reported by governmental and non-governmental agencies, about 150,000 people in Kosovo have some sort of disability, and about half are thought to be children of school age.¹⁶⁴ From this overall number, only about 1,000 are included in the schooling system. Consequently, a remarkably high number of children with disabilities are thought to remain out of the schooling system, meaning that no organized and systematic effort is being made to develop their abilities and skills. According to the most recent data, 2,354 children with disabilities receive social assistance based on their disability.¹⁶⁵ It is troubling that a remarkably high number of children with disabilities who receive social assistance do not attend any form of education. Ignoring the possibility that some of the children who receive social assistance are of pre-school age or have completed primary school, this still leaves many children with disabilities who could be enrolled in the education system with optimal effort.

There is no reliable data on the number of children with disabilities who are not enrolled in school. Some estimates are based on international standards and practices regarding the approximate number of people with disabilities within a population. Other estimates are based on assumptions and local context. The population census¹⁶⁶ completed earlier this year included a series of questions regarding the respondents' possible limitations in performing daily tasks or leading a functional life. Preliminary data from the census were published soon after the fieldwork was completed, but these numbers provide only an estimate of the overall number of Kosovo inhabitants, including a breakdown by municipalities. A full overview of the census data is expected around mid-2012.

Enrolment in Education

The Law on Primary and Secondary Education urges cooperation between parents, school authorities and children when deciding whether a child should be enrolled in a regular or in an attached class. However, if no attached class is available in the area but it has been determined that the child's needs will be best met in an attached class, neither the law nor the other government guidelines provide any solution.

Travelling teachers were introduced in 2007 as a supporting mechanism for teachers at regular schools who are involved in teaching disabled children in ordinary or attached classes. In 2007, six travelling teachers participated in a study visit to Finland in order to learn more about the responsibilities of their counterparts in the host country.¹⁶⁷ Travelling teachers work in special schools/resource

¹⁶² Strategy for Development of Pre-University Education in Kosovo 2007-2017, Ministry of Education, Science and Technology.

¹⁶³ Ibid., Objective 4, Activity 4.3.4.

¹⁶⁴ Assumptions based from *Justice Denied, The State of Education of Children with Special Needs in Post-Conflict Kosovo*, UNICEF/Engjujt 2009.

¹⁶⁵ Interview with Bexhet Gagjiqi, Advisor to the Minister, Ministry of Labour and Social Welfare.

¹⁶⁶ It should be pointed out that Kosovo Serbs living in Northern Kosovo boycotted the census.

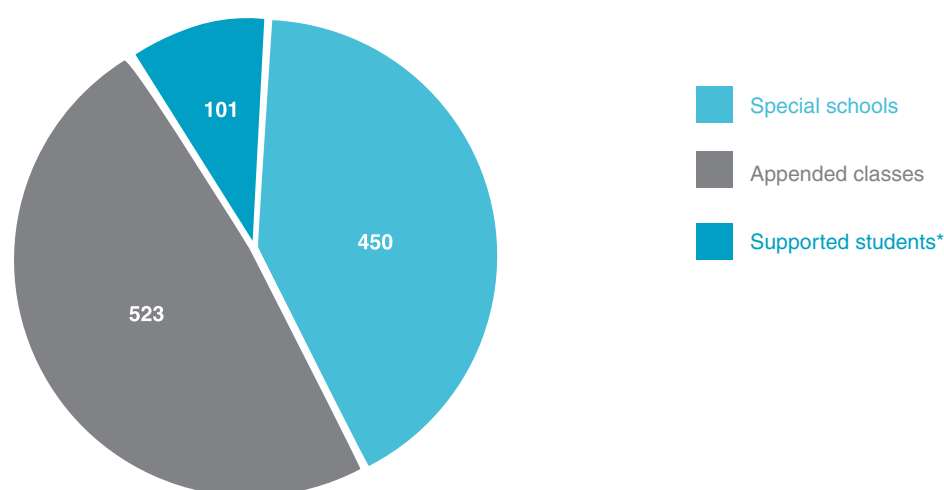
¹⁶⁷ MEST Work Report for 2007, Ministry of Education, Science and Technology.

centres and provide technical support to special-needs children and their teachers.¹⁶⁸ They also organize workshops for teachers employed at regular schools who may have a disabled student in their class. In particular, these workshops present a methodology for working with children with intellectual disabilities. The travelling teachers from the Lef Nosi Resource Centre in Prizren identified 68 children with disabilities, and provided support to 27 children from various ethnic groups enrolled in the regular education system.¹⁶⁹

Data from the field show that the concept of travelling teachers from special schools/resource centres who come to help teachers at regular schools in need of assistance in working with disabled children is still in the process of being institutionalised.¹⁷⁰ During 2011, a total of 101 children with disabilities at regular schools received support from resource centres through travelling teachers.¹⁷¹ Forty-five of the children who received help from a travelling teacher had intellectual disabilities.

Statistics from the 2010/2011 academic year show that a total of 1,074 children with disabilities were enrolled in school. The largest number of children with disabilities in the education system was enrolled in appended classes, followed by special schools, and then by ordinary classes with the assistance of travelling teachers. According to the statistics for the 2008/2009 academic year, a total of 25 municipalities in Kosovo had attached classes or special schools offering primary and secondary education, with a total of 150 classes.¹⁷² Three municipalities had special secondary schools – 16 classes with 83 students.¹⁷³

Number of special-needs children enrolled in school



*Through travelling teachers

Although recent years have seen an increase in the total number of disabled children enrolled in the education system, there have been considerable oscillations in the reported number, which raises doubts as to whether the increase in the number of disabled students is truly the result of systematic and proactive work towards all-inclusive education. During the last couple of years, there has also been an increase in the total number of students enrolled in the education system, i.e., there is a correlation between the number of children with disabilities and the number of all students enrolled.

¹⁶⁸ Strategy Plan for Organizing All-inclusive Education of Children with Special Needs in Pre-university Education in Kosovo, 2010-2015, Ministry of Education, Science and Technology.

¹⁶⁹ Interview with Mr. Ilaz, Director of the Lef Nosi Resource Centre in Prizren.

¹⁷⁰ Interview with MEST official and directors of the Perparimi (Prishtine) and Lef Nosi (Prizren) resource centres.

¹⁷¹ Statistics on Education 2010/2011, Ministry of Education, Science and Technology.

¹⁷² Education Statistics, 2008/2009, Statistical Office of Kosovo, page 81.

¹⁷³ Ibid., 85.

Data on school enrolment, all children and children with disabilities

School year	Number of children in special education ¹⁷⁴ – Total	Number of children in attached classes	Total number of children in primary and secondary education	Ratio between children enrolled in regular schools/ classes and those in special schools and attached classes
2002/2003	557	NDH	389,323	.0014
2003/2004	601	NDH	407,295	.0015
2004/2005	858	434	400,697	.0021
2005/2006	797	514	397,499	.0020
2006/2007	814	456 ¹⁷⁵	411,355	.0020
2007/2008	891	NDH	417,080	.0021
2008/2009 ¹⁷⁶	835	752 ¹⁷⁷	415,919	.0020
2009/2010	1,179 ¹⁷⁸	791 ¹⁷⁹	411,990	.0029
2010/2011	1,074	624 ¹⁸⁰	408,410	.0026

Note: We were unable to retrieve data on education from a single source, as the data published by the Ministry of Education did not use the same reporting standards over the years. There are some discrepancies in the data, which may have resulted from the use of different methodologies to record the number of children enrolled in the schooling system.

The ratio between students enrolled in special schools and those enrolled in attached classes is about even: the number of children with intellectual disabilities is 213 in special schools and 281 in attached classes. In both types of special education, children with intellectual disabilities represent about one half of the children enrolled in school.¹⁸¹ In relation to the data from 2009/2010, we may note that whereas at special schools the number of children with intellectual disabilities is equal to the number children with other types of disabilities, in attached classes children with intellectual disabilities make up more than half of the students.¹⁸² This reflects repeated and awkward changes in data collection, resulting in differences in reporting.

¹⁷⁴ The data on special education includes the number of children attending level 1 and 2 of basic (primary) education.

¹⁷⁵ The data on appended classes were taken from Indicators and statistical data on education, 2004-2007, MEST, 2008. This report contains numerous discrepancies with the data reported by the Statistical Office of Kosovo regarding the number of students in primary and secondary schools for the period 2004 to 2007: the MASHT report gives 940 for the 2004/2005 school year, 884 for the 2005/2006 academic year, and 925 for the 2006/2007 academic year.

¹⁷⁶ The data for 2002 to 2009 were taken from Statistics in Education 2008/2009, Statistical Office of Kosovo, page 107.

¹⁷⁷ Statistics on Education 2008/2009, Statistical Office of Kosovo.

¹⁷⁸ First draft on implementation of National Disability Action Plan in Kosovo, Office for Good Governance, Prime Ministers Office.

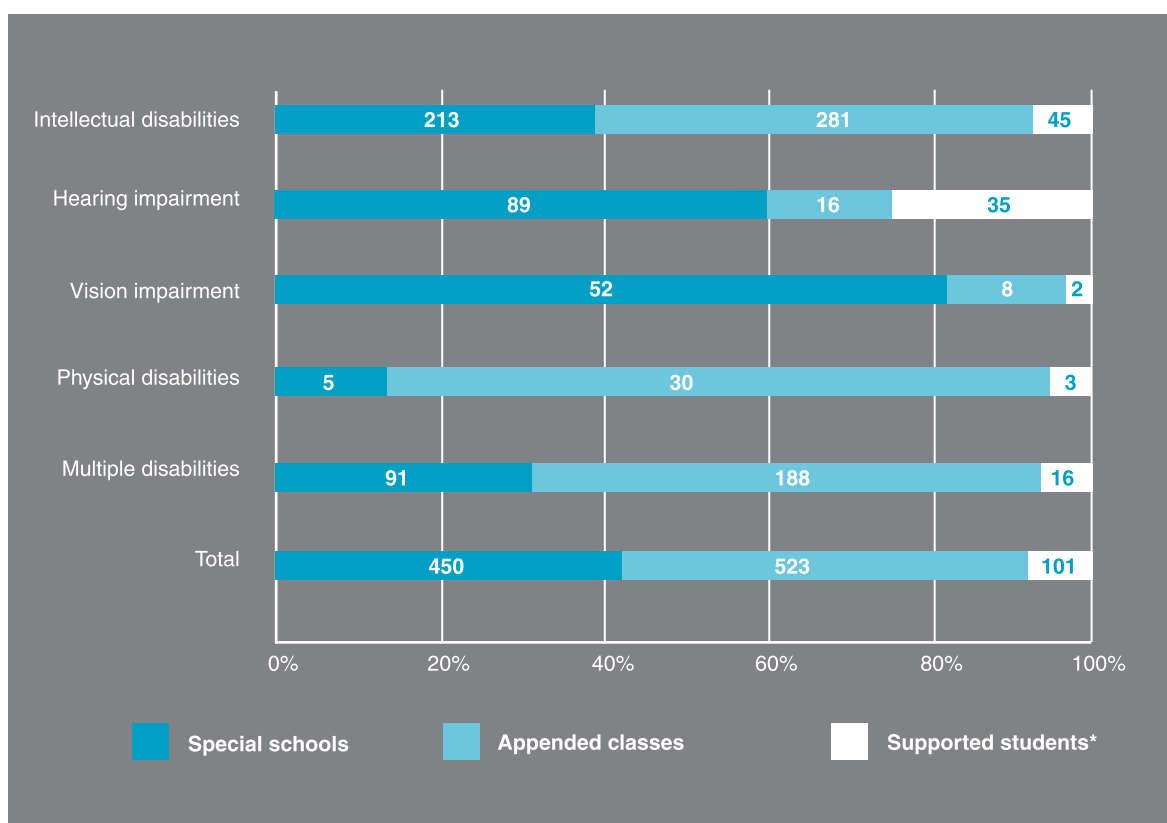
¹⁷⁹ Statistics on Education 2009/2010, Statistical Office of Kosovo.

¹⁸⁰ The statistics regarding children enrolled in appended classes in the 2010/2011 school year include the new category of children with special needs enrolled in regular classes and supported in the teaching process by travelling teachers, as identified by Resource Centres (formerly Special Schools).

¹⁸¹ Statistics on Education in Kosovo, 2010-2011, Management Information System in Education, Ministry of Education, Science and Technology.

¹⁸² National Action Plan for People with Disabilities in Republic of Kosovo 2009-2011, Office for Good Governance, page 37-38. However, according to data from the Kosovo Statistical Office, 791 children with special needs were enrolled in special schools and appended classes during the 2009/2010 academic year. It is possible that the national action plan also included children enrolled at regular schools. This calls into doubt its accuracy, as children who have any sort of "abnormality" (such as wearing glasses, or repeating a grade) may be classified as having a special need.

Type of disability and number of children enrolled in special education



*Through travelling teachers

Inclusive Education at Work

Despite the Ministry of Education's commitment and the existence of a legal framework for all-inclusive education, the educational resources available to most children with disabilities do not provide them with many opportunities. Despite positive change in the recent past, there is still no guarantee of organized transportation to a school with attached classes. The lack of attached classes represents a serious barrier to enrolling disabled children in school, mainly because teachers at regular schools/classes often lack the knowledge and skills for working with children with intellectual disabilities, or school directors do not accept children with disabilities at their schools. On the other hand, when attached classes are available, disabled children may consider enrolling in them. If a child with disabilities is enrolled in an attached class, continuous efforts are made to transfer the child into a regular class in order to meet the goal of all-inclusive education. The Law on Pre-University Education explicitly states that the principle of all-inclusive education forms a cornerstone of the country's educational system, and that special schools are justified only if regular school is deemed impractical. Although the law envisions the transition from attached classes to regular classes, once students meet standards of conduct and achievement, the number of such cases is reported to be insignificant.¹⁸³

Education at Institutions; After-School Activities

As a rule, residents at the SISH and at community-based homes have limited opportunities for pursuing education. Data from the field show that only a small number of SISH residents have completed primary education. A similar situation exists at the community-based homes.

¹⁸³ Indicators and Statistical Data on Education, 2004-2007, Ministry of Education, Science and Technology.

There are only a relatively small number of children in institutions. These children lived at the community-based homes in Shtime/Stimlje and Gracanice/Gracanica, both managed by MLSW. Both homes provide shelter for 10 children each, meaning that the total number of children placed in these institutions is 20. According to the Law on Primary and Secondary Education, the Ministry of Education is responsible for organizing education for people who have deprived of liberty, inmates in psychiatric wards, and children who are hospitalised longer periods of time.¹⁸⁴ It remains unclear who is legally responsible for monitoring their inclusion in the educational process, as such children might not be enrolled in regular or attached classes (administered by the local school district), nor are they listed in any of the specified MEST categories for offering continuous education. Whereas the legal provisions regarding compulsory education hold parents responsible if a child does not attend primary education, it does not include any responsibilities for guardians. Data from the field show that three of the children living in the community-based home in Shtime/Stimlje completed (special) primary school, while all the others are past the mandatory school age.¹⁸⁵ At the children's community-based house in Gracanice/Gracanica, two children attend regular school and two have attended special school in the past.¹⁸⁶ In Shtime/Stimlje, three of the residents are adults, whereas in Gracanice/Gracanica all residents are older than 18 years of age, but continue to live there because they cannot be placed elsewhere.

A study commissioned by UNICEF¹⁸⁷ on the prevailing conditions in special education looked at various environments, including regular classes, attached classes and special schools. One of the study's findings was that on many occasions, children were assigned tasks on an individual basis, which is a positive sign demonstrating that teachers are aware of and utilising individual planning and taking into consideration the needs of each student. However, although this practice seems to have become widespread among teachers in the special education sector, teachers develop individual education plans informally, and additional technical assistance is greatly needed.

Individual Education Plans (IEPs)

The use of Individual Education Plans remains one of the key challenges for all teachers in the special and regular education systems. All students with special education needs are entitled to a dedicated IEP for their individual needs. However, the law does not require the use of individual education plans, but merely suggests their use to the extent possible. Not even the new law on pre-university education has made IEPs mandatory for students with special needs. Data from the field show that IEPs are not widely used in the education system, and they are not used as often as they should. Out of four observations in special education classes, only one teacher had developed IEPs and was able to show one to the researchers; the other teachers gave the researcher a general verbal description of his approach to each student.¹⁸⁸ MEST is in the process of publishing a manual to help teachers compile IEPs. It is currently being used as part of a pilot project at 70 schools throughout Kosovo¹⁸⁹ – an alarming indication as to the serious delay in implementing the Law on Primary and Secondary Education since being passed by parliament back in 2004.

A 2007 MEST document includes an overview of current legislation related to inclusive education, as well as a short description of practices for people with disabilities in the USA.¹⁹⁰ One remarkable feature of this document is that it offers additional details on the functioning of the commissions for evaluating and developing individual educational plans. It also provides details related to the practical application of these two concepts within the school environment. The document also offers insight into several aspects of individual schoolwork by describing several milestones that teachers should keep in mind while setting their tasks. All of these offer a remarkable resource for teachers when working with their students. It is difficult to say how widely this manual has been disseminated

¹⁸⁴ Law on Primary and Secondary Education, Article 37.

¹⁸⁵ Interview with Mrs. Elife Rexhepi, manager of the children's community-based home in Shtime/Stimlje.

¹⁸⁶ Interview with Mrs. Biljana Stanojevic, manager of the children's community-based home in Gracanice/Gracanica.

¹⁸⁷ Justice Denied: The State of Education of Children with Special Needs in Post-Conflict Kosovo, UNICEF/Engjujt 2009.

¹⁸⁸ Class monitoring was performed in appended classes at Zejnel Hajdini, Prishtine; Perparimi Resource Centre, Prishtine/Prishtina; and Lef Nosi Resource Centre, Prizren.

¹⁸⁹ First Evaluation Report on Implementation of the National Disability Action Plan for People with Disabilities in Kosovo, Office for Good Governance, Prime Minister's Office.

¹⁹⁰ Booklet for Identifying, Assessing and Education of Children with Special Needs, Ministry of Education, Science and Technology, 2007.

among teachers and to what extent the principles contained therein have been implemented. It is worth mentioning that the manual also offers a model for IEPs, and describes several procedures for achieving optimal results when compiling an IEP. It is difficult to assess the extent to which this template has been used by special education teachers; the results from the field show that many of the key principles described in the document are not frequently applied. This model seems to be very useful and helpful to teachers, both as a good reference point for the student's specific conditions and for determining the anticipated achievement results. It includes a series of relevant baseline information about the student, including short-term achievement plans and additional services that the student can and should make use of. It is unclear whether this document is being currently used widely by teachers engaged in working with special-needs children, and whether the Ministry of Education is working to make this document readily available to and mandatory for teachers. The document's status is described in an administrative guideline approved in 2007, which states it was "adopted and approved for use" by the Ministry of Education.¹⁹¹

Reflections on the Education System by Students with Disabilities

A survey¹⁹² of children in special education provides insight into how they experience their time at school and the learning process. Most of the children reported that their teachers divided them into groups to work on school-related tasks (16 out of 20 students agreed at least to some extent). Almost all of the surveyed students (15 agreed and another 4 agreed somewhat with the statement) reported that their teachers were willing to listen to their ideas, which is a very encouraging circumstance ensuring a pleasant environment for the students. A similar number of surveyed students reported that their teachers enjoyed helping them with their schoolwork. Five students did not agree with the statement that their work is exhibited on the walls so that other people can see it. The students demonstrated differences in opinion when it came to liking the schoolwork they were given a chance to do, with the responses distributed equally across all three possible answers. The students also reported name-calling among classmates – seven students agreed that other children in the class called them names that they did not approve of, and two other students agree somewhat; 11 students reported there were not called names. All the students exhibited a sense of pride and achievement when they did well on their schoolwork. The students described their teachers as excellent mediators: 17 of agreed their teachers helped them resolve disputes. When homework is assigned, all the students understand what they are supposed to do (only three replied that they sometimes might have trouble understanding). The teachers are seen as caring and attentive to the students' needs: 18 students reported that their teachers like to know about their activities at home. On a similar note, all students confirmed that their teachers were interested in their whereabouts if they missed a day of school.

Programs for Supporting Inclusive Education in Kosovo

In line with the principles of inclusive education, several projects and initiatives have been implemented over the years with the aim of building sufficient capacities for these policies' successful operationalisation. In the realm of special education, the Finnish Group (FSDEK) has been particularly active and has contributed greatly to the entire process. FSDEK served as a special consulting body for compiling policies and implementing strategies related to designing and implementing an education system oriented towards all-inclusive practices. The developed practices and strategies are on a par with those implemented in western countries, particularly Scandinavia.¹⁹³

Much of the training of special education teachers was organized and performed by the Finnish Group, which was established and commissioned to provide support in special education after the

¹⁹¹ Administrative Guideline No. 9/2007, Professional Assessment of Children with Special Needs, Article 7, Ministry of Education, Science and Technology. It must be pointed out that article 7 of this Administrative Guideline, and not the booklet for identification, assessment and education of children with special needs, discusses the development Individualized Education Programs.

¹⁹² For more on the methodology, see Annex I.

¹⁹³ Transition from Special Schools to Recourse Centres, MEST/FSDEK II, 2004.

establishment of UNMIK. It also served as an advisory body for the Ministry of Education in organizing and upgrading special education. To date, FSDEK has helped to train more than 4,800 teachers in inclusive education.¹⁹⁴ Many other international and local organizations have contributed to special education as well. Along with FSDEK, these include Save the Children, the Kosovo Education Centre, the MEST and other key stakeholders who have provided workshops in the field of special education. Also, the University of Prishtina's Department of Education offers workshops in special education, and the regular study program for this degree includes an a mandatory and two elective courses on special education. It is also encouraging to see that most of teachers in special education have attended at least some workshop on special education.¹⁹⁵

Persons with disabilities should get an education, attend different courses, find employment, and not stay locked up in homes. All of this can be achieved with the support of families, society, the government, municipality, organizations, etc.

Ne per Ne advocate, Peje/Pec

In order to improve the lives of persons with disabilities, the government should increase pensions and draft policies for people with disabilities to enter mainstream schools instead of attached classes.

My recommendations for all people preventing us from having a better life are: "Don't beat us, don't look down on us, consider us equal to everyone else in the society".

Ne per Ne advocate, Hani i Elezit/ General Janković

Conclusion

The legal framework regulating education in Kosovo aspires towards inclusive education. However, the findings of this study show that the strategy of inclusive education, as currently being implemented in Kosovo, has had poor results. Many elements of inclusive education are still not being properly addressed.

The number of special-needs children in school is still just a small fraction of the total number of children with special needs in the country. In addition, current laws encourage school segregation by placing children with special needs in special education instead of trying to find the resources and implement the systemic changes necessary for inclusive education. These factors show that Kosovo is still seriously lagging behind in meeting international standards and is not fulfilling its duties for working in accordance with the objectives set by the UN CRPD.

The segregation of special-needs children in special schools – in particular, the placement of children with intellectual disabilities in special schools or in appended classes – prevents children with disabilities from participating freely in community life on an equal basis with other children, and keeps them from being an important and active asset to school programs along with the other students.

Quite often, special education teachers lack the necessary training for working with children with special needs. Teachers are not providing the conditions needed by the children in order to develop their capabilities, talent and creativity, and they do not care for or promote the child's physical and mental potential. Teachers are not familiar with the principles of including disabled children into ordinary classes and treating them equal to the other students. Schools often do no more than provide disabled children a physical place for them to spend their time, but do not offer an engaging, satisfying and fulfilling participation in school activities.

Enrolment in primary schools is mandatory for all children in Kosovo. Parents are responsible for enrolling their children in school, and the law prescribes certain disciplinary measures for parents

¹⁹⁴ Mapping Policies and Practises for the Preparation of Teachers for Inclusive Education in Contexts of Social and Cultural Diversity, Kosovo Country Report, European Training Foundation, 2010.

¹⁹⁵ Justice Denied: The State of Education of Children with Special Needs in Post-Conflict Kosovo, UNICEF/Engujt 2009.

who fail to do so. However, these provisions of the law are not enforced. There is only minimal community engagement, especially when it comes to involving parents in the process of deciding on their child's enrolment or participation in school life.

When enrolling in school, disabled children must be assessed by an evaluation commission formed at the municipal level. Although they have been mentioned in legal documents for many years, these commissions are not functional. As a result, the assessment of children with special needs is still done without the existence of any predefined and approved procedure from the Ministry of Education. Children with intellectual disabilities are assessed via a battery of psychological tests of unclear content, which produce unsupportive and inconclusive results. To date, no psychological assessment tests have been localized in the Albanian language for use in Kosovo.

The number of children with a detailed and up-to-date Individual Education Plan is low, and teachers are only vaguely aware of how to use this tool.

Recommendations

The government must develop strategies for achieving better results in the field of inclusive education. Children with disabilities who are not enrolled in the education system must be identified using alternative sources, and further innovative measures must be undertaken in order to increase their enrolment in the education system.

The legal infrastructure, including government policies, must be in full harmony with the principles of inclusion. All elements leading to segregation and the restricted participation of disabled children in the decision-making process and preventing their equal treatment must be removed.

School authorities must show a clear willingness to embrace the principles of inclusive education. Teacher training in the field of inclusive education must be mandatory, and must be accompanied by continuous efforts at developing skills for working with disabled children.

Convenient and safe transportation for children with special needs must be universal, free and sustainable.

All children with special needs enrolled in school must have an Individual Education Plan, which serves as a baseline for individual work with the child. The IEP defines the objectives of the child's school courses, outlines strategies for achieving better results, and provides information pertinent to the child's performance at school. It is imperative that teachers working with special-needs children receive the relevant resources, including the timely dissemination of instructional manuals and booklets on developing and implementing individual education plans. The supporting materials for the individual education plans must be compiled in such a way so that teachers can find the information they need for their class work. The material must be self-explanatory, user-friendly, and use best practices from the field. Workshops on individual education plans must form an integral part of developing the teacher's skill for working with special-needs children.

Municipal evaluation commissions must be formed and become fully functional as soon as possible. Appropriate training for these commissions should be provided, and the commissions' work must be supervised. The work of these evaluation commissions must bear in mind the principles of inclusive education, and the team's expertise must be focused on developing pedagogical procedures that will yield the best results in each individual case.

WORK AND EMPLOYMENT

Legal and Policy Analysis

Kosovo's constitution guarantees all citizens with the right to work.¹⁹⁶ It also guarantees the right of each person to choose their vocation and the place where they want to work.¹⁹⁷ Compulsory work is prohibited¹⁹⁸, and the constitution recognizes the right of people to choose the place and type of work. The Labour Law explicitly prohibits any form of discrimination, direct or indirect, of people with disabilities.¹⁹⁹ This ban on workplace discrimination also applies to promotions and professional advancement if the disabled person can adequately perform his work-related duties. The UN's definition of disabilities is included in the Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities, which was passed in late 2008. The law includes the following categories for people with disabilities:

- > recipients of social benefits or a disability pension,
- > persons without any professional work-related training who receive disability benefits or a pension,
- > beneficiaries of war or civil invalid protection,
- > disabled students aged 15 to 18, including persons who use sign language and the Braille alphabet,
- > youth aged 15 to 18 with developmental disorders who receive social assistance,
- > disabled individuals older than age 18 categorized on the basis of other legal provisions.²⁰⁰

The law on the retraining of people with disabilities anticipates helping disabled people develop their own individual capacities in order to acquire marketable skills that will make them more competitive in the labour force. The support provided under this law includes a broad range of supporting resources, such as an initial evaluation of the person's working skills, or technical assistance and follow-up related to job applications. People with disabilities – along with women, minorities and youth – are given priority in attending workshops, and trainees must be enrolled as jobseekers with the Public Employment Service.²⁰¹

Protecting and Promoting Disabled People's Right to Employment

In 2010, the Ministry of Labour and Social Welfare improved the training and employment opportunities for people with disabilities through a series of administrative guidelines aimed at improving the provision of services to people with disabilities. Among other things, these guidelines established standard operating procedures for enrolling disabled people in vocational training and for promoting the employment rights of people with disabilities.²⁰² They also confirmed that people with disabilities were to be given priority in training, rehabilitation and employment opportunities.

The Labour Law contains several additional provisions specifying the need to protect marginalized groups: women, youth, and the disabled. The law guarantees people with disabilities the right to continue working as long as they are capable of performing their duties without any need for professional rehabilitation.²⁰³ If a disabled employee's health deteriorates to the point that he can no longer perform previous his tasks, but he then successfully completes professional rehabilitation to perform

¹⁹⁶ Constitution of the Republic of Kosovo, Article 49.

¹⁹⁷ Constitution of the Republic of Kosovo, Article 50.

¹⁹⁸ Constitution of the Republic of Kosovo, Article 28.

¹⁹⁹ Official Gazette of the Republic of Kosovo, No. 90/10, Labour Law, No. 03-L-212, Article 5.2.

²⁰⁰ Official Gazette of the Republic of Kosovo, No. 47/09, Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities, No. 03/L-019, Article 4.

²⁰¹ Kosovo Education Strategic Plan 2011-2016, Ministry of Education, Science and Technology.

²⁰² In particular, Administrative Guideline No. 03/2010 for Procedures for the Right to Skills Development, Retraining and Employment of People with Disabilities, Ministry of Labour and Social Welfare.

²⁰³ Labour Law, Article 47.1.

new tasks, the employee shall be considered competent to perform those new tasks.²⁰⁴ Employers must provide people with disabilities who have received professional rehabilitation training with an appropriate working position.²⁰⁵ If a disabled employee refuses to accept the new tasks that have been offered to him under these provisions of the law, then the employer may terminate the working contract.²⁰⁶ People with disabilities can find protection under this law, but may also face additional disadvantages in the employment sector. Current legislation represents an important support for increasing the training and employment opportunities for people with disabilities. However, these protective measures may also dissuade employers from hiring people with disabilities. Employers are required to find a suitable job within the company for their disabled employees if the employees are no longer able to perform the duties of their existing job. By law, disabled employees are entitled to be placed in another job within the company after undergoing a professional training. In view of the fact that most of private companies in Kosovo are small enterprises with fewer than five employees, if a worker cannot perform his existing working duties, it is unlikely that the employer will be able or willing to accommodate them in a different position.

People with disabilities are protected from performing heavy work, overtime work, and working the night shift.²⁰⁷ Disciplinary measures are foreseen for employers who violate this provision of the law.²⁰⁸

The Labour Law also governs the rights of the parents of disabled children. Parents of disabled children cannot be fired or forced to change jobs because they are absent from work in order to look after a disabled child. Dismissals are allowed only in cases of collective termination.²⁰⁹

The law also guarantees equal pay for equal work, but this explicitly applies only to gender and does not include equal pay for equal work when other disparities are involved.²¹⁰

Vocational Training

The Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities governs the rights and conditions under which disabled people can access the labour force. It includes a reasonably positive provision for increasing disabled people's access to the labour market. This provision states that all employers (from public as well as private sectors) must hire at least one person with disabilities for every fifty employees.²¹¹ The law also stipulates penalties for violations of this provision, in the form of a fine to be paid into Kosovo's consolidated budget. These fines are then supposed to be invested in promoting employment opportunities for people with disabilities.²¹² The law also offers incentives for entrepreneurs to hire people with disabilities in the form of reduced taxes and customs fees. If employing a person with a complete disability (100%) who is also receiving a disability pension, "the pension is used to pay for a personal assistant at work."²¹³ Employers who hire people with disabilities may apply to receive a financial stimulus from the country's budget.²¹⁴

Current legislation relating to the employment of people with disabilities does not distinguish among different types of disabilities and the support that should be provided for each. As a result, there are no established policies or strategies for people with intellectual disabilities. However, the Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities envisions that the rehabilitation process should involve an evaluation of intellectual abilities, after which the person receives professional training in order to improve working and social skills until he finds employment.²¹⁵ This

²⁰⁴ Ibid., Article 47.2.

²⁰⁵ Ibid., Article 47.3.

²⁰⁶ Ibid., Article 47.4.

²⁰⁷ Official Gazette of the Republic of Kosovo, No. 15/07, Law on Occupational Safety, Health and the Working Environment, No. 2003/19, occupational safety, health and the working environment, Article 4.

²⁰⁸ Ibid., Article 15.

²⁰⁹ Labour Law, Article 76.

²¹⁰ Ibid., Article 55.3.

²¹¹ Law on vocational ability, rehabilitation and employment of people with disabilities, Article 12.1.

²¹² Ibid., Article 12.3.

²¹³ Ibid., Article 18.

²¹⁴ Ibid., Article 19.

²¹⁵ Ibid., Article 8.2.5.

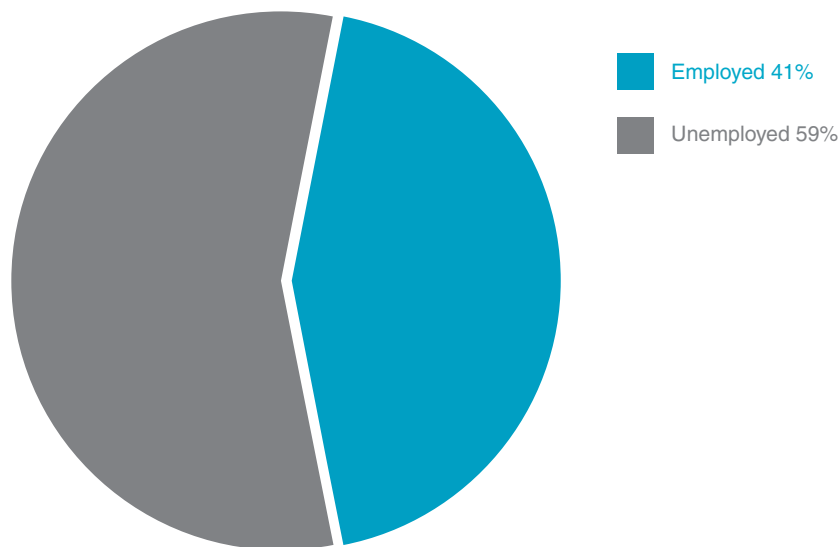
learning process should include “professional teaching, planning, and use of preferred technologies.”²¹⁶ In terms of being able to choose one’s job, the choice of professional training is restricted to the list provided by the Centre for Vocational Training, based on the applicant’s abilities and skills.²¹⁷

Analysis of Practice

The reported unemployment level in Kosovo is alarmingly high. According to various sources, each using a methodology for defining employment, the unemployment rate ranges from 37% to 45% of active individuals, and employment is reported to be just over 26%.²¹⁸ There are also indicators that youth and women have even higher rates of unemployment.²¹⁹ To date, no large-scale study has been performed into the unemployment rate among people with disabilities, but the general assumption is that it is very high. Considering the country’s vulnerable economy and scarce foreign investments, it is unlikely that unemployment problem in Kosovo will improve in the near future.

Each municipality operates an employment office that acts as a bridge between jobseekers and job providers. These offices have access to a consolidated database containing most important information on all registered applicants. According to the Department of Labour’s 2010 annual report, a total of 335,260 unemployed people were registered throughout all Kosovo.²²⁰ Due to a lack of reliable data on the country’s population, the total active population can only be estimated to range from 811,000 to 861,000. This results in an unemployment rate of 37% to 41%. Every year since 2001, approximately 1,500 to 2,000 people²²¹ have registered with the unemployment bureau; of these, between 400 and 900 find employment. These employment arrangements may last for just a few of months, but also for longer periods of time. More than 90% of all registered unemployed individuals have had this status for more than 12 months.

Employment of the economically active population



In this remarkably impoverished market of employment opportunities and a large number of people seeking employment, people with disabilities remain on the margins in terms of possibilities for pursuing employment. At the end of 2010, a total of 1,937 people with disabilities were registered as unemployed, with 133 new applicants registered during 2010 alone. There was a slight increase of 1.8% in the number of disabled people registering as unemployed as compared to the previous

²¹⁶ Ibid., Article 8.2.8.

²¹⁷ Ibid., Article 9.

²¹⁸ Work and Employment, and Statistical Office of Kosovo, Kosovo Labour Survey, Ministry of Labour and Social Welfare.

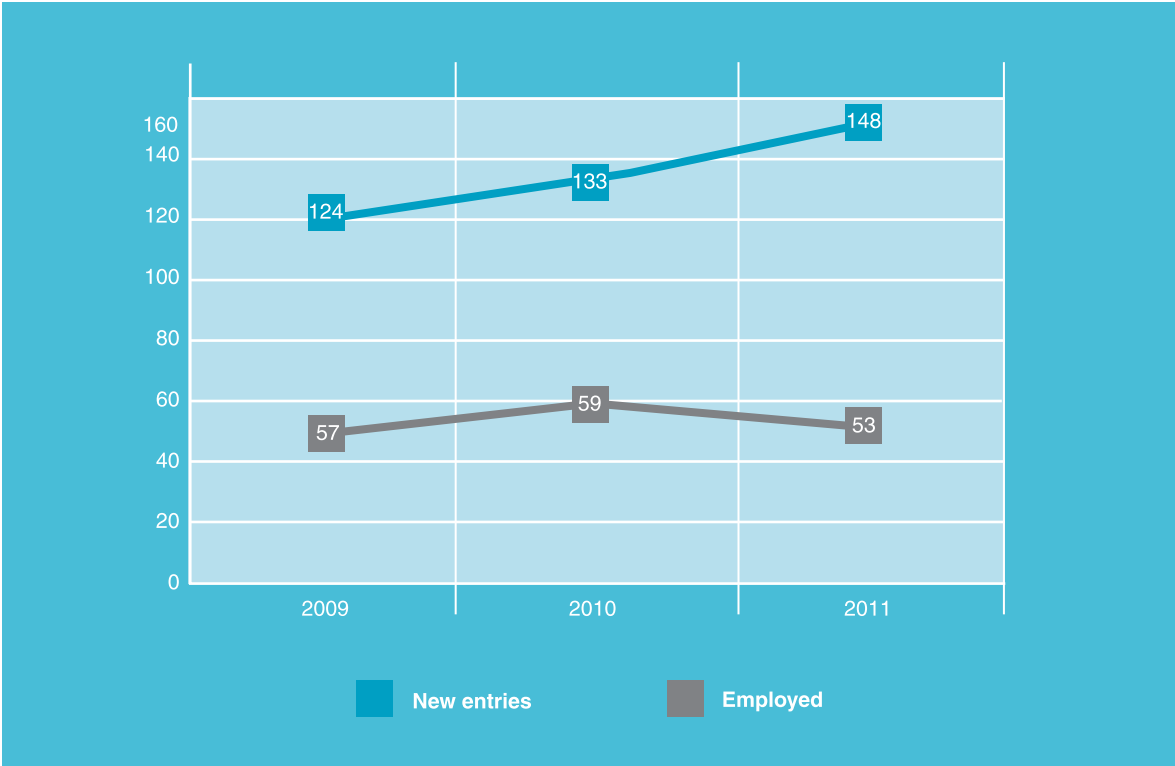
²¹⁹ Kosovo Human Development Report 2010, United Nations Development Program, gives the unemployment rate among youth at 73% and a staggering 81% among women.

²²⁰ Work and Employment 2010, annual report, Department of Work and Employment, Ministry of Labour and Social Welfare.

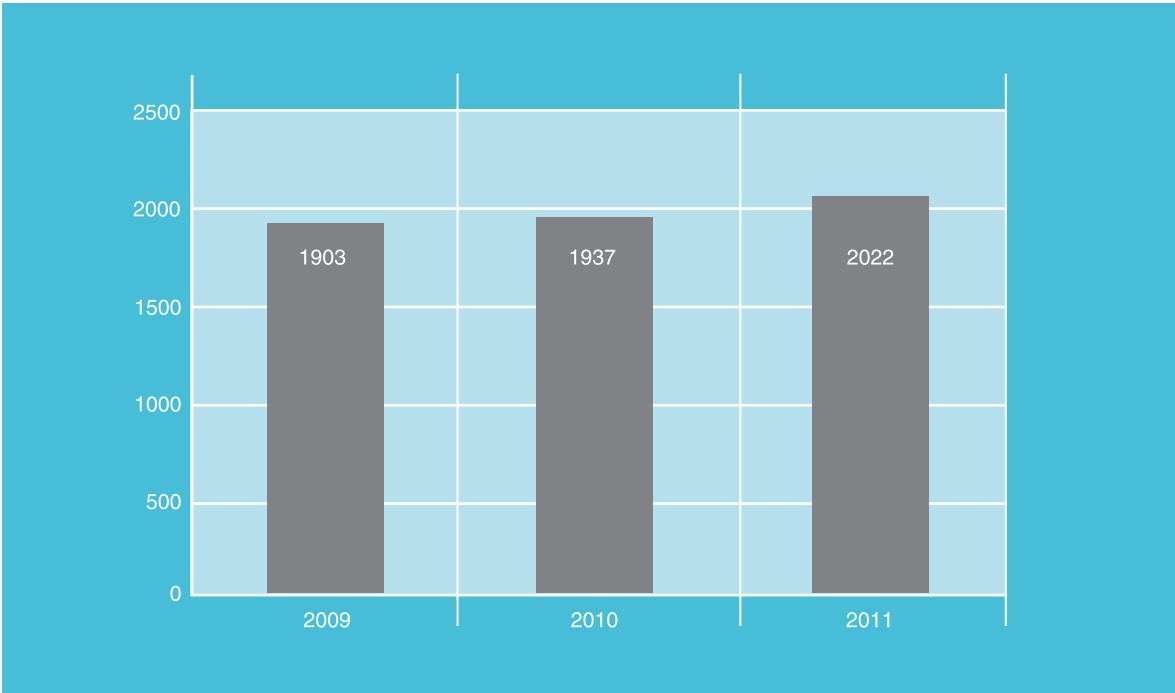
²²¹ Statistics from the education system show that each year about 25,000 to 30,000 pupils enrol in school.

year. Considering the total number of unemployed people with disabilities, the number of applicants for 2010 can be considered to represent the average number of new registrants per year. That year, 59 people with disabilities found employment – a slight increase over the previous year (by 3.0%).

Number of new registrants and newly hired people with disabilities



Number of people with disabilities registered as unemployed



Factors Diminishing Employment Opportunities for People with Disabilities

Employment among people with disabilities is assumed to be at a very low rate. People with disabilities face adverse circumstances on the labour market, heavily influenced by the inequalities experienced in all other related fields, such as education and accessibility. According to government officials, the major obstacle faced by disabled people is the extremely low demand for new employees, a lack of funding for stimulating the employment of disabled people, and a lack of willingness among companies and organizations to employ people with disabilities.²²²

Information from professional training centres reveals that the modular programs offered to job applicants are developed on the basis of market research. The results of this research were used by the advisory board to suggest what kind of workshops the MLWS should provide.²²³

Deprivation of legal capacity does not necessarily restrict a person's access to the job market. The legal infrastructure still lacks a clear definition of the restrictions imposed on persons who have been deprived of legal capacity. The introduction of partial deprivation gives the courts the option of retaining some but not all of the person's rights. Considering the obstacles faced by people with intellectual disabilities when accessing the labour market, legal deprivation is likely to be another limiting factor, one that often proves to be insurmountable.

Rehabilitation and Employment

Vocational training of people with disabilities is organized and managed by Centres of Vocational Rehabilitation. There are eight centres in the country's seven administrative districts, including one in North Mitrovica, plus five other mobile centres. These centres offer a diverse range of training programs, including training for plumber, electrician, computer literacy, business administration, agriculture, construction, and a specialized programme on the Braille system.²²⁴ In 2011, a total of 2,757 people attended training programmes organized by these centres.²²⁵ According to data obtained from the regional Centres of Vocational Rehabilitation, people with intellectual disabilities only rarely participate in the training modules. At the regional centre in Ferizaj/Urosevac, no person with intellectual disabilities participated in any training programme, whereas in Peja/Pec, three people with intellectual disabilities have attended trainings since 2005.²²⁶ Fifty-five people with disabilities attended vocational training during this year, at one of the country's eight regional training centres.²²⁷ There are no national data on the type of disability and enrolment in the vocational program. The annual report also refers to an agreement reached training centres and a disabled people's organization, according to which the centres would organized an interpreter training programme for sixty visually impaired and fifteen hearing impaired unemployed people. We may thus infer that, at least in 2010, the training services were not tailored towards and did not reach a significant number of people with intellectual disabilities. It is interesting to note that 53 of the 55 trained applicants were male, but more than half of employed people with disabilities during 2010 were female (61%).

²²² Interview with Mr. Hafiz Leka, Ministry of Labour and Social Welfare.

²²³ Interview with Mr. Rexhe Gashi, Director of Centre for Professional Training in Peje/Pec.

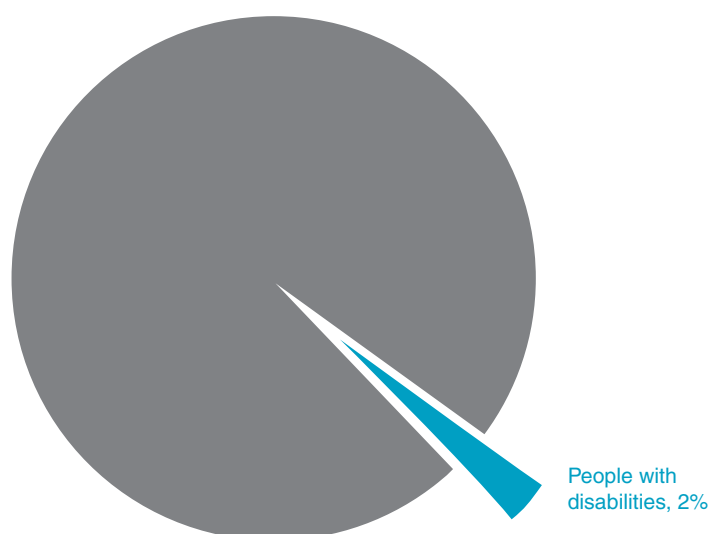
²²⁴ Interview with Mr. Gani Ismajli, Leader of the sector for quality assurance of trainings and certification, Ministry of Labour and Social Welfare.

²²⁵ Information on Workforce in Kosovo, November, 2011, Department of Work and employment, Ministry of Labour and Social Welfare.

²²⁶ Interview with Mr. Rexhe Gashi, Director of Centre for Vocational Rehabilitation in Peje/Pec and Mrs Fatmire Salihu, Deputy Director of Centre for Vocational Rehabilitation in Ferizaj/Urosevac.

²²⁷ Work and employment 2010, Yearly report 2010, Department of Work and Employment, Ministry of Labour and Social Welfare.

Vocational training participants



Employment Assistance from the Non-Governmental Sector

Kosovo Mental Disability Rights International (KMDRI) and the United Nations Development Fund joined forces to organize a programme for promoting the employment of people with intellectual disabilities carried within the framework of the Active Labour Market Programme (ALMP). The programme helped 45 people with intellectual disabilities find employment. Project beneficiaries came from municipalities throughout the country and included three people with intellectual disabilities from the Shtime Special Institute, all of whom found employment. The disabled people managed to find employment at private companies and public institutions, including retail stores, a municipal assembly, primary schools, as a hairdresser, at a car wash, a wood production company, a coffee shop and at non-governmental organizations.

KMDRI and ALMP report that the companies and organizations consider the beneficiaries to be valuable employees and that their experience with the project has been remarkable positive. According to one of the beneficiaries, "I feel utmost joy in my working place and I hope that through this initiative others will be persuaded that people with intellectual disabilities can work and live independently."

This initiative remains the first and the only one to be implemented in Kosovo. Its objective was to provide direct employment support for people with intellectual disabilities. The UNDP's Active Labour Market Programme has been in place since 2005, and active policies for employment implemented in collaboration with the Ministry of Labour and Social Welfare and other disability organizations has made possible the employment of more than 7,500 jobseekers, including disabled beneficiaries. The project has been financially supported by the governments of Norway and Denmark, and by local institutions.

The best way for persons with intellectual disabilities to be integrated in the community is for society to support them and to pressure institutions to find jobs for people with disabilities.

Employment has helped me a lot, I can go out every day, have an organized life, earn my own money and not ask from anyone. In order for everyone to have a better life, we need family and the communities where we live to support our rights and to support our education and employment.

Ne per Ne advocate, Hani i Elezit/General Jankovic

During the months of October and November of 2009, I had an opportunity to work for a business in Shtime. I enjoyed the work very much and had a good time. I want to work again. I also had the opportunity to attend K-MDRI workshops conducted during the implementation of their project, from which I learned a lot.

Resident of Shtime / Štimlje Special Institute

Conclusion

Kosovo's constitution recognizes the universal right to employment, which guarantees the right to work in a place and vocation of one's choosing. Current legislation promotes the employment of people with disabilities, and protects them from having to work in severe harsh conditions that may affect their well-being. There has been a steady improvement in the country's legislation regarding disabled people's access to the labour market. Several laws have been passed in relation to the employment of disabled, as well as measures for stimulating their employment in the private sector. It has been widely noted that these laws are not being properly enforced. Experience has shown that it is not enough to only develop the legal infrastructure for dealing with the issue of employment. The laws represent a potential for the future creation of innovative projects that will encourage the private and public sectors to employ people with disabilities. It remains the government's responsibility to develop the implementation mechanisms for existing legislation.

People with disabilities face highly adverse employment circumstances in accessing the labour market. They have suffer from discrimination and segregation in other spheres of life, such as education and healthcare, for most of their lives, and as a result they face unequal chances of accessing the labour market. The problem of employment requires a multilateral approach that helps people with disabilities receive opportunities in all areas of life, just like other people.

The greatest number of registered jobseekers has little or no formal education, meaning that disabled people can increase their chances of employment by receiving some form of training in a particular field. Since being established, the country's centres for vocational rehabilitation have provided training to numerous people, and further efforts should be made in order to increase the number of disabled people participating in these vocational programmes.

Little is known about the status of disabled people in Kosovo. An extremely small number of disabled people, and people with intellectual disabilities in particular, are able to access the labour market and vocational training.

Official government statistics on unemployment include only people have registered with the employment offices located in each municipality.

The law requires public- and private-sector employers to hire at least one disabled person for every fifty employees. This law is not being implemented in either sector.

International organizations, in partnership with Kosovo institutions and the non-governmental sector, have managed to improve employment opportunities for people with disabilities.

Recommendations

It is necessary to regularly gather comprehensive data on the factors that influence the lives of disabled people. We need a systematic and comprehensive investigation of the abilities, predispositions and potential of disabled people to access the labour market.

Disabled people must be encouraged to register with employment offices and be listed in the government database. An increase in the number of registered individuals may prompt the government to pay more attention to reducing unemployment among people with disabilities. In addition, centres for

vocational training should offer more programs that respond more accurately to the needs of disabled people, and should introduce programmes that might generate more employment opportunities.

The public and private sector need to cooperate more closely in employing people with disabilities. The private sector must be informed on the training opportunities provided by the centres for vocational rehabilitation, from which they can benefit by hiring employees who have trained to perform required tasks.

The government should actively develop mechanisms for implementing legal provisions requiring both the private and the public sector to hire people with disabilities. The number of disabled people employed in the public sector should be addressed immediately, and the mechanisms for monitoring employment and recruitment in the public sector should be developed. We need measurable results in achieving the fair participation of people with disabilities in the workforce.

The government must increase its cooperation with disability organizations, and use best practices for the employment of people with disabilities from previously implemented projects as a good model to be followed.

ANNEX I

Methodology

The methodology applied by this report includes several tasks aimed understanding the many different perspectives on the situation for each of section in the report. The information used in the analysis was obtained in two separate manners: a) through a desk-review analysis of legislation and reports on the situation of people with intellectual disabilities in Kosovo, and b) qualitative and quantitative techniques. Whereas the desk-review component served as a cornerstone for each section's legal analysis, the data obtained by qualitative and quantitative means was mainly used to add insight to practical section of the analysis.

In all sections, the desk-review opened with a description of the rights and obligations found in the constitution. This is followed by an analysis of the key laws related to the issue at hand, with an emphasis on the most pertinent issues regulated by the laws in question. We also describe any administrative or other documents issued by governmental bodies that address or are related to the issue of citizens with intellectual disabilities. Finally, we use reports from other governmental and non-governmental bodies to present major findings concerning the current situation and to show what concerns have been raised.

We used qualitative and quantitative techniques to gather information from the field. The qualitative component involved primarily the use of in-depth interviews with officials from the relevant ministries, public institutions that provide services to people with intellectual disabilities (residential institutions such as the Special Institute in Shtime, community-based homes, or public service providers such as teachers or municipal officials), court judges, and so on. Other qualitative sources are focus group discussions with family members, support persons, and self-advocates with intellectual disabilities. We also engaged in several monitoring visits to institutions and observed the teaching process in classes consisting of children with intellectual disabilities. The quantitative component involved a short survey with students with intellectual disabilities, primarily inquiring about their experiences with the schooling system.

SERBIA

Serbia is a constitutional democracy, with the rule of law and separation of powers between the executive, legislative and judiciary. In accordance with Article 16 of the country's Constitution, generally recognized principles and rules of international law and accepted international documents form an integral part of the country's legal system and are implemented directly. Further, Article 18 of the Constitution assures that the human rights and minority rights guaranteed by the Constitution, generally accepted rules of international law, and confirmed international covenants and laws are implemented directly. Laws may prescribe the manner in which these rights are realized only if so envisaged within the Constitution and if necessary due to the nature of the right in question. Laws may not affect the substance of the guaranteed right. Of particular importance is the Article 21 of the Constitution prohibiting direct and indirect discrimination on any basis, explicitly including mental and physical disability.

Serbia ratified the Convention on the Rights of Persons with Disabilities, including the convention's Optional Protocol, on 31 July 2009.¹ In recent years, major improvements in Serbia regarding the status of persons with disabilities were foremost seen in normative changes. These include the adoption of the Law on Preventing Discrimination Against Persons with Disabilities,² the Strategy for Improving the Position of Persons with Disabilities in Serbia (2007-2015),³ the Law on Prohibition of Discrimination,⁴ the Law on the Basics of Education,⁵ and the Law on Professional Rehabilitation and Employment of Persons with Disabilities.⁶

Nevertheless, the conditions for persons with disabilities in Serbia remain very poor. Though persons with disabilities have become more "visible" in recent years, their position in society is still far from equal to persons without disabilities. Serbia's Poverty Reduction Strategy places persons with disabilities in the general population on the bottom level of poverty and social exclusion. Among persons with disabilities, persons with intellectual and psychosocial disabilities are even more disadvantaged as a result of prejudiced attitudes that create various legal and administrative barriers.

¹ Official Gazette of the Republic of Serbia – International Contracts, No. 42/2009 from 2 June 2009.

² Official Gazette of Republic of Serbia, No. 33/2006

³ Official Gazette of Republic of Serbia, No. 1/2007

⁴ Official Gazette of Republic of Serbia, No. 22/2009

⁵ Official Gazette of the Republic of Serbia, No. 72/2009 and 52/2011.

⁶ Official Gazette of the Republic of Serbia, No. 36/09.

EQUAL RECOGNITION BEFORE THE LAW

Legal and Policy Analysis⁷

The Constitution of the Republic of Serbia states that every person in Serbia has the right to legal recognition. With the age of majority (18), a person gains the capacity to independently decide on his or her rights and obligations.⁸

In Serbia, the issue of legal capacity and the placement of adults under guardianship is regulated by decades-old, outdated legislation. The relevant provisions are not found in one place, but are scattered throughout many laws and regulations. The basic regulations regarding legal capacity and guardianship are found in the Family Act and in the Non-Contentious Proceedings Act (adopted in 1982 and changed several times since, but without significant changes in this particular area). In addition, certain regulations can also be found in the Law on Health Protection, the Law on Social Protection, the Law Ensuring Social Security of Citizens, the Criminal Law, Election Laws, and the Law on Obligation Relations, among others. Generally, these laws specify the status of legally deprived persons in the specific areas that they regulate.

Basis for and Effects of Deprivation of Legal Capacity and Extension of Parental Rights

In addition to the Constitution, legal capacity and maturity (which is attained at the age of 18) are regulated by the Family Law.⁹ Full legal capacity is attained at the age of 18 or by getting married before the legal age with the court's permission. Parental rights cease when the child turns 18 or gains full legal capacity before this age.¹⁰ The law recognizes three types of limitations to the exercise of legal capacity: full deprivation of legal capacity, partial deprivation of legal capacity and extension of parental rights.

According to this law, an adult person who, "as a result of illness or difficulties in psychological or physical development, [is] incapable of normal reasoning and therefore unable to care independently for his or her own rights and interests" may be fully deprived of his or her legal capacity.¹¹ Legal capacity of these persons is equal to the legal capacity of a younger minor (child below the age of 14).¹²

The law also provides that an adult person who, as a result of illness or difficulties in psychological or physical development, "directly threatens his or her own rights and interests or the rights and interests of other persons" may be partially deprived of his or her legal capacity.¹³ Legal capacity of these persons is equal to that of an older minor (child between the age of 14 and 18).¹⁴

Similarly, parental rights may be extended before a child reaches the legal age of majority if a child "is incapable of taking care of and protecting his or her rights, or if he/she threatens his or her rights and interests through his or her actions, as a result of illness or difficulties in psychological or physical development."¹⁵ The law does not explicitly equate the status of persons over whom parental rights have been extended with the status of persons who have been partially or fully deprived of legal capacity. However, since the individual in question retains the legal status of a minor and is not

⁷ Large part of this analysis has been taken from Kosana Beker:

Pravo da donesem odluku, Belgrade, May 2010, Inicijativa za Inkluziju VelikiMali.

⁸ Constitution of the Republic of Serbia, Article 37.

⁹ Official Gazette of the Republic of Serbia, No. 18/2005 and 72/2011, Family Law, Article 11.

¹⁰ Ibid., Article 84, paragraph 1, points 1 and 2.

¹¹ Ibid., Article 146, paragraph 1.

¹² Ibid., Article 146, paragraph 2.

¹³ Ibid., Article 147, paragraph 1.

¹⁴ Ibid., Article 147, paragraph 2.

¹⁵ Ibid., Article 85.

granted legal capacity in any area, we may state that the status of persons over whom parental rights have been extended is equal to that of a fully decapacitated person.

Consequences of the Deprivation of Legal Capacity or Extension of Parental Rights

According to the Family Law, persons fully deprived of their legal capacity may undertake only legal actions of minor significance and cannot undertake any legal actions by which they are assigned rights or obligations.¹⁶ The consequences of the extension of parental rights are the same as being fully deprived of legal capacity. On the other hand, the precise legal actions that a person who has been partially deprived of legal capacity can or cannot undertake must be determined by the court.¹⁷

As mentioned above, the deprivation of legal capacity automatically affects decision-making in many different areas of life. The aforementioned general restriction contained in the Family Law is concretised by other laws, which forbid persons from:

- entering into contracts (Law on Obligation Relations, Article 999) – by default this prevents any buying or selling of property and any employment;
- entering into marriage (Family Law, Article 18);
- exercising parental rights (Family Law, Article 77 (1), Article 91(1) and Article 113(3);
- independently taking legal action (Law on Judicial Procedure, Article 74);
- voting (Law on the Election of the President of the Republic, Article 2);
- gaining citizenship (Law on Citizenship in the Republic of Serbia, Article 18);
- deciding to terminate a pregnancy (Law on the Procedure of Pregnancy Termination in Health Institutions, Article 2);
- deciding on medical procedures (Law on Health Protection, Article 35);
- receiving an organ transplant (Law on Organ Transplantation, Article 21);
- opening a shop (Law on Private Entrepreneurial, Article 8);
- being insured on an equal basis with others (General Conditions for Insurance from the Consequences of Accidents, Dunav Insurance a.d.o, Belgrade, Article 5),
- volunteering (Law on Volunteering, Article 12).

This list includes only several examples in order to show the extent to which the effects of legal capacity are deeply and widely ingrained within the legal framework of Serbia. For a more in-depth list of legal consequences, please refer to *Pravo da donesem odluku*.¹⁸ This publication shows that the legal presumption is that the legal system treats persons whom a court has deemed to be incapable of sound reasoning as being incapable of deciding on many aspects of their own lives.

The Procedure Leading to the Deprivation of Capacity

Persons are deemed legally incapacitated and placed under guardianship mechanism through two connected, though legally separate processes – the deprivation of legal capacity is a court procedure (under the Law on Non-Contentious Procedure¹⁹), and the appointment of a guardian by the guardianship authority is an administrative procedure (under the General Administrative Law²⁰). The definitions of legal capacity, guardianship and extension of parental rights are contained in the Family Law.

The procedure for the deprivation of legal capacity is initiated and carried out by the court in its official capacity or upon the initiative of the guardianship authority, spouse, child or parent if the legal conditions for the deprivation or limitation of legal capacity are met.²¹ The procedure may also be

¹⁶ Ibid., Article 64, paragraph 1.

¹⁷ Ibid., Article 147, paragraph 3.

¹⁸ Kosana Beker: *Pravo da donesem odluku* [The Right to Make a Decision], Belgrade, May 2010, Inicijativa za Inkluziju VelikiMali, pages 24-27; also available in Serbian from <http://www.velikimali.org/doc/Publikacija.pdf>.

¹⁹ Official Gazette of the Socialist Republic of Serbia, No. 25/82 and 48/1988 and Official Gazette of the Republic of Serbia, No. 46/95 and 18/2005, Non-contentious Proceedings Act.

²⁰ Official Gazette of the Socialist Republic of Serbia, No. 33/97, 31/2001 and Official Gazette of the Republic of Serbia, No. 30/2010, General Administrative Law.

²¹ Non-contentious Proceedings Act, Article 32, paragraph 1.

initiated by grandparents or grandchildren if they live with that person in a family unit.²² The person who stands to be deprived of his or her legal capacity may also initiate proceedings if he or she can comprehend the purpose and legal consequences of such action.²³ One very important point is that the law specifies that the proposal must contain and be based on facts and evidence established with certainty or thought to be probable.²⁴

The decision on the deprivation of a person's legal capacity is made in non-contentious proceedings,²⁵ and is based on the opinion of at least two independent medical experts regarding the person's mental state and capacity to reason.²⁶ Their examination must occur in the presence of a judge.²⁷ Based on this provision of the law, we conclude that it was the lawmakers' intention that a judge be present when the person is examined by the medical experts. This may be because the persons who are usually the subject of such proceedings are persons with psychosocial and intellectual disabilities who are vulnerable and susceptible to abuse.

The law is also clear regarding the relevant person's participation in the proceedings. According to the law, the court must hear the person who is the subject of the legal capacity proceedings; if he or she is institutionalised, then the hearing must be held in the institution.²⁸ However, the court can decide not to hear a person "if it is determined that this might be detrimental to his or her health or if the hearing is made impossible by the mental or physical condition of the person."²⁹ The vague nature of this clause leaves room for an arbitrary interpretation. The mere existence of this exemption from the rule that the person concerned must be heard leads to concerns that the courts may justify their decision not to hear persons with psychosocial disabilities because it "might be detrimental to his or her health". An analysis of this exemption should therefore involve identifying the cases in which a hearing may endanger the person's state of health. The presumption must be that those cases, if they exist at all, are very rare.

If it does not hear the person concerned, the court must hear his or her guardian, temporary representative, the initiator of the proceedings or other persons who can provide important information about the person's life, behaviour and other circumstances.³⁰ If necessary, the court may obtain such information from other individuals or organizations.

A legally binding court decision on the deprivation of legal capacity must be submitted to the guardianship authority immediately.³¹ This decision is noted in the birth registry,³² and if the person has any assets or owns any property, the decision is also noted in the public real estate registry.³³

A person who has been deprived of his or her legal capacity may appeal the court's decision regardless of his or her mental state.³⁴ This provision is extremely valuable in that the persons being can seek legal remedy themselves, but it loses its practical significance in cases where a person is not heard, when a person does not receive the court decision regarding the deprivation of legal capacity, and/or if he or she requires assistance in understanding the decision or the whole process.

Reinstatement of Legal Capacity

The court's decision on legal capacity is made for an indefinite period of time. There is no obligation to review the decision. The reinstatement of legal capacity is possible, and the law provides that the court can, in its official capacity or on the initiative of the guardianship authority or other authorized

²² Ibid., Article 32, paragraph 2.

²³ Ibid., Article 32, paragraph 3.

²⁴ Ibid., Article 33, paragraph 1.

²⁵ Family Law, Article 149, paragraph 1.

²⁶ Non-contentious Proceedings Act, Article 40, paragraph 2.

²⁷ Ibid., Article 38, paragraph 2. Unless it takes place in a health institution.

²⁸ Ibid., Article 36, paragraph 1.

²⁹ Ibid., Article 36, paragraph 2.

³⁰ Ibid., Article 37.

³¹ Family Law, Article 149, paragraph 2.

³² Ibid., Article 150, paragraph 1.

³³ Ibid., Article 150, paragraph 2.

³⁴ Non-Contentious Proceedings Act, Article 40, paragraph 3.

persons including the person deprived of legal capacity, make a decision to restore legal capacity.³⁵ However, since the law does not require that the initial decision undergo periodical review, the court has no opportunity to receive information that may lead to the reinstatement of legal capacity.

There are additional practical shortcomings to the reinstatement of legal capacity. While the law allows for a person who has been deprived of legal capacity to initiate the process to reinstate legal capacity, it does not oblige the court or state bodies to inform the persons concerned about the existence of this possibility. Moreover, the law provides that the reinstatement of legal capacity is possible “if the reasons for its deprivation cease to exist.”³⁶ However, if the disability itself is the underlying reason for deprivation of legal capacity, this regulation does little to help persons regain their legal capacity, since the disability will not simply disappear. In such cases, the criteria for the reinstatement of legal capacity are not fulfilled.

Guardianship – Procedure, Types and Roles

Within 30 days of the court’s decision to deprive a person of legal capacity, the guardianship authority³⁷ assigns a guardian to the person in order to protect his or her rights and interests. Persons who are considered capable of reasoning may propose their own guardian.³⁸ However, since “incapacity for normal reasoning” is a basis for the complete deprivation of legal capacity, it follows that persons who have been fully deprived of legal capacity are not consulted when they are assigned a guardian. The final decision includes a guardianship plan, the name of the guardian, and the decision on the person’s placement. If the person has assets or owns property, the permanent commission within the guardianship authority registers and assesses the property’s value.

Legal safeguards state that a person cannot be named guardian if the court concludes that his or her interests are contrary to the interests of the person under guardianship.³⁹ The decision may also be appealed to the Ministry of Labour and Social Policy within 15 days of receipt of the decision by the guardian or a person with a legal interest in the matter.⁴⁰ However, this unfortunate wording, which states that a person without legal capacity may appeal the decision him- or herself, makes the procedure unclear. The relevant Ministry has confirmed that it indeed accepts appeals from the concerned persons themselves even when they are not supported by the guardians or guardianship authorities.⁴¹ Such an important decision should not be left to the discretion of state bodies, however.

The Family Law also defines the types of guardianship and the guardian’s obligations and rights. It allows for: one person to be appointed guardian for one person, one person to be appointed guardian for several persons deprived of legal capacity (guardian to several wards), directors and employees of residential institutions to be appointed guardians to the persons placed in such institutions (collective guardians), the guardianship authority to be assigned guardian (direct guardians) and temporary guardians.

The guardian’s duty is to conscientiously take the steps necessary to ensure the care of the person under guardianship. Guardians must endeavour to make their wards capable of leading an independent life.⁴² This also means that guardians should initiate the procedure for the reinstatement of legal capacity when the disabled individual is again capable of independent living. Also, the guardian is obliged to visit the person and to inform the guardianship authority about the living conditions of the individual who has been deprived of legal capacity.⁴³ Although guardians must visit the adult under their care, the frequency of such visits remains undefined. Other important guardian duties include representing their wards in legal matters, acquiring funds for living, regularly inspecting the

³⁵ Family Law, Article 148.

³⁶ Ibid., Article 148. On a similar note, article 86 defines the same criterion for ceasing of the extended parental rights.

³⁷ In the social welfare system in Serbia, the role of the guardianship authority is assigned to the centres for social work

³⁸ Family Law, Article 127.

³⁹ Ibid., Article 128, paragraph 3 and 4.

⁴⁰ Ibid., Article 333, paragraph 5.

⁴¹ Public conference organized by MDRI-S and Belgrade Centre for Human Rights: Legal capacity as a human right in Serbia, Belgrade, 28 October 2011.

⁴² Family Law, Article 136, paragraph 2.

⁴³ Ibid., Article 136, paragraph 3.

ward's property and managing this property. With the prior permission of the guardianship authority, guardians may dispose of⁴⁴ the property belonging to the person under guardianship.⁴⁵ Also, with the approval of the guardianship authority, income from person's property may be used to pay for the costs of guardianship, namely the guardian's fees.⁴⁶

There is no adequate control mechanism for the guardian's work. Guardians are required to submit reports to the guardianship authority on an annual basis (regular report), whenever the guardianship authority asks for one (specific report), and after the guardianship ends (final report). The report should contain information about the person under guardianship, his or her living conditions, health, education, and other important information including facts about the management of the person's property, the final balances of any property and the previous period's income and expenses.⁴⁷ Although there is an obligation to report to the guardianship authority, it is difficult to assess the guardian's behaviour and obligations, especially in cases in which the guardian is an employee of the guardianship authority. Another problematic fact is that the guardianship authority that appoints the guardian is solely responsible for controlling and assessing the guardian's work.

If a person has no relatives or if the relatives are unwilling to be guardians, the guardianship authority appoints one of its employees to perform the duties of guardian. This approach is unlikely to produce satisfactory results, especially with such loosely defined duties. This situation is further exacerbated by the shortage of social workers at Centres for Social Work in Serbia.

An appeal may be filed with the guardianship authority regarding the guardian's work either directly by the ward if he or she is considered capable of reasoning, or by another person with a legal interest.⁴⁸ The guardianship authority may recall a guardian immediately and must do so within 30 days of determining that he or she is neglecting certain duties, abusing his or her authority or if circumstances arise that disqualify him or her from being a guardian.⁴⁹

The law does not contain any clear safeguards, and there are no sanctions or penalties if guardians fail to fulfil their obligations, such as visiting their wards. Also, it must be emphasized that no provision exists which would oblige the guardian to consult with the person deprived of legal capacity on any aspect of that person's life.

⁴⁴ Ibid., Article 140, paragraph 2. Disposing (raspolaganje) as opposed to managing (upravljanje) is the ability to buy & sell property.

⁴⁵ Ibid., Article 140, paragraph 3. The guardian can only apply the capital of the property to cover living costs or if there exists some other compelling interest.

⁴⁶ Ibid., Article 143 and 44. The guardian has a right to reimbursement of costs and a fee. Such costs are primarily paid out of the income of the person under guardianship, unless such payment threatens the interests of the person.

⁴⁷ Ibid., Article 142.

⁴⁸ The same comment can be applied here as in the cases of appeals against initial appointment of guardians.

⁴⁹ Family Law, Article 133.

Analysis of Practice

The exact number of persons deprived of legal capacity in Serbia is unknown. However, the records of Centres for Social Work indicate that in 2010, a total of 11,721 adult and elderly persons in Serbia were under permanent guardianship.⁵⁰ The same records show that since 2007, the number of adults and elderly under guardianship has been steadily increasing.

Number of adults under guardianship⁵¹

Category/Year	2007	2008	2009	2010
Number of adults (including elderly) under guardianship	9,365	10,205	11,393	11,721
Number of adults (including elderly) under temporary guardianship	5,233	6,813	6,550	6,823
Total	14,598	17,018	17,943	18,544

These figures do not include persons over whom parental rights have been extended, since they have not been formally deprived of legal capacity. Nevertheless, these individuals face the same restrictions in the exercise of their rights. Furthermore, this data fails to indicate the various types of legal capacity deprivation at the most basic level: the number of persons who have been fully or partially deprived of legal capacity. Additionally, no cumulative data is found on the areas in which persons may or may not make decisions and take actions, nor is there any data on the property that was divested from persons by the transfer of right to property disposition. Although the local authorities are required to keep records on the status of persons in their municipalities (births, deaths, changes in legal capacity, property), the state does not seem to place much importance on creating a unified database for the population of individuals who have been deprived of legal capacity.

Until recently, the practice of legal deprivation was also virtually unknown to the general public, aside from anecdotal evidence from occasional cases that became known to civil society or to the ombudsman's office in Serbia. These individual stories showed that there are cases in which guardians abuse their powers and that the authorities do not always apply safeguards, particularly in regard to the management of money and assets.

Case Law in the Field of Legal Capacity

In order to shed light onto this practice, as a first step it was necessary to examine judicial procedures in order to come to findings on:

- Profile of persons who are deprived of legal capacity;
- Basis for deprivation;
- Ratio of partial to total deprivation;
- Critical points causing courts to decide on partial instead of total deprivation;
- Application of procedural safeguards as provided by the law;
- Effectiveness of access to courts for persons once deprived of capacity;
- Effectiveness of regulation of reinstatement of capacity;
- Effectiveness of person's representation in proceedings; and
- Relationship between capacity deprivation and institutionalisation.

The data obtained on judicial practice in Serbia jointly by the MDRI-S and the Belgrade Centre for Human Rights⁵² provided us with findings that answer the above questions.

⁵⁰ Report on work of centres for social work for the year 2010, Belgrade, March 2011, page 46. <http://www.zavodsz.gov.rs/PDF/izvestavanje/IZVESTAJ%20CSR%202010%20-%20FINAL.pdf>

⁵¹ Ibid., 46-47.

⁵² See Annex I for information on methodology.

According to the findings, a significant majority of cases concerned deprivation of legal capacity (around 90%), while close to 10% were cases of extension of parental rights. An insignificant number of cases were instigated for the reinstatement of legal capacity (0.5%). This low number confirms that persons who are deprived of their legal capacity lack sufficient access to courts.

Case law on legal capacity according to the request for procedure

Category/Frequency	# of cases	% of cases
Deprivation of legal capacity	899	90.2%
Extension of parental rights	93	9.3%
Reinstatement of legal capacity	5	0.5%
Total	997	100%

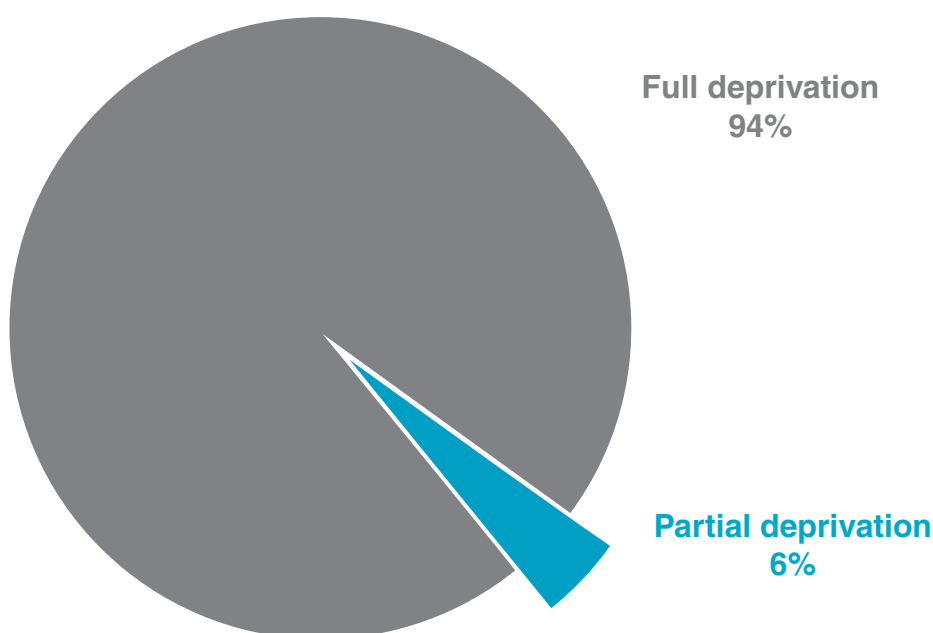
It is also worth noting the statistics of court rulings. Out of 899 requests for depriving a person of legal capacity, this request was denied in only 13 cases.⁵³ Similarly, in all 93 requests for extension of parental rights the courts ruled without exception to extend parental rights. Additionally, partial deprivation is rarely used. Out of all 899 requests for the deprivation of legal capacity, only 54 (6.1%) ended in partial deprivation – i.e., the court limited specific areas of decision-making, for the most part as regards decisions related to medical treatment or the management of finances and assets. Usually, the court specified more than one area of limited decision making. In four cases, however, the court failed to specify any areas in which a person could or could not act, thus leaving them de facto fully deprived of legal capacity despite the fact that the court's decision was one of partial deprivation. The same concern applies for those cases (12) in which the court decided on partial deprivation but then concluded that the person could not engage in any legal contracts. Significantly, we found no pattern in how decisions on partial versus full deprivation were made. In other words, it can never be predicted when a court is likely to limit a person's ability to decide and act in only certain areas as opposed to all areas of life. One possible reason for this can be found in the general rule that the courts make their decisions within the limits of the specific legal request. This means that it is important for petitioners to not submit a request for full or unspecified deprivation if they want to signal to the court that they are seeking only minimum restriction of capacity.

Case law on legal capacity according to the court decision

Category/Frequency	# of cases	% of cases
Full deprivation of legal capacity	834	83.7%
Extension of parental rights	93	9.3%
Partial deprivation of legal capacity	53	5.3%
Rejection of request to deprive legal capacity	12	1.2%
Rejection of request to reinstate legal capacity	2	0.2%
Reinstatement of legal capacity	3	0.3%
Total	997	100%

⁵³ Out of these 13 rejections, seven rejections were due to a procedural error, and in three cases requests were rejected before examining the case in merit.

Ratio of full vs. partial deprivation



Partial deprivation: Areas of limited decision-making

Decision-making restricted in the area of ⁵⁴ :	# of cases
Medical treatment/medical therapy	27
Disposing of finances and/or property	27
Entering into all legal arrangements	12
Disposing of finances and/or property of large value	11
Institutionalisation – choice of place and living conditions	9
Family life – marriage, raising children	4
Not specified	4
Participating in judicial and administrative procedures	2
Work and employment	1

The findings show that the persons most frequently subjected to the procedure are those with intellectual disabilities, followed by persons with psychosocial disabilities. It should also be noted that the case law shows that the extension of parental rights is applied to persons (minors) with intellectual disabilities only. A common disability is dementia, which is present as a cause or one of the causes in 76 cases of deprivation. Persons with physical or sensory disabilities are rarely subjected to the procedure (this occurred in only four cases) unless they also possess some other, usually intellectual disability. In those cases, the intellectual disability is the primary focus of the assessment on legal incapacity. It is important to note that in almost all the cases reviewed (99%), the person's disability was clearly stated, usually in the form of a medical diagnosis.

⁵⁴ One person may have restricted legal capacity in more than one area.

Case law on legal capacity according to the type of disabilities

Disability/frequency	# of cases	% of cases
Intellectual disabilities	450	45.3%
Psychosocial disabilities	308	31.0%
Combined disabilities	129	13.0%
Dementia	76	7.6%
Addiction	17	1.7%
Unknown	10	1.0%
Physical disability	4	0.4%
Total	994⁵⁵	100%

Despite the fact that the law mandates this practice, we found no decision for which it was clear that the judge was present at the person's examination by two medical experts. In a striking 87% of cases, the court did not hear the person, and in 84% of cases the judge did not even attempt to establish visual contact with the person whose deprivation of legal capacity was being decided on. While visual contact is certainly not sufficient for assessing a person's competencies, it should be an indispensable starting point. Without even seeing the person whose competencies have been evaluated and presented to the court, the court fully divests itself of the opportunity to verify this evaluation – and more importantly fails to engage in communication with and hear the person as required by the law. In fact, the data shows clearly that the exception provided by the law (which allows the court not to hear the person whose legal capacity was being decided) has been turned into a general rule.

For most of the cases in which the person was heard by a judge, the decision contains no information on what the person actually said regarding the procedure, whether he or she understood the procedure in the first place, and if he or she did not understand the procedure, whether or not any steps were taken by the court in order to familiarize the person with the procedure and its consequences. This should be a crucial role of the court, since people who are subjected to these proceedings and their families are frequently not informed or are misinformed about the exact consequences that capacity deprivation and placement under guardianship will have on the person's rights and everyday life. The people do not know what kind of decisions they will not be able to make on their own, or who will be making them on their behalf.

Case law on legal capacity according to participation in a procedure

Disability/frequency	# of cases	% of cases
Person not heard	768	77.3%
Person heard	125	12.6%
Intention to hear the person ⁵⁶	101	10.1%
Total	994	100%

⁵⁵ The sample has since decreased by three cases in which the request was rejected before the case was examined.

⁵⁶ This category comprises cases in which a hearing was considered but not performed (the judge decided not to hear the person based on the experts' recommendation, without seeing the person) and cases where a hearing was attempted but given up (the judge actually posed question(s) to the person, but received no verbal answer). While both categories could be effectively classified as either being heard or not being heard, this was not always evident from the text of the decision. The decisions' insufficient information or insufficiently clear wording made it difficult for us to deduce whether the person participated in the procedure or not. Therefore, this category is left separate, signifying a general intention of the court to hear a person. This lack of clarity in the text of the decisions as regards the person's participation may indicate the courts' general perception that this issue is not of high importance.

Case law on legal capacity according to visual contact with a judge

Disability/frequency	# of cases	% of cases
Person seen by judge	160	16.1%
Person not seen by judge (not evident) ⁵⁷	834	83.9%
Total	994	100%

This general lack of awareness of the implications of legal capacity deprivation might serve to illuminate the lack of objection to the request for deprivation by the person herself or himself. However, the large percentage of cases in which a temporary guardian or representative never expressed a formal objection to a proposal for capacity deprivation demonstrates the ineffectiveness of legal representation. It also indicates that people commonly accept that this is a procedure that one does not object to. What is more, in almost 28% of cases, the guardianship authority (Centre for Social Work) played a double role as initiator of the procedure and as the temporary representative of the person in question. Interestingly, we identified four cases in which the person subject to capacity deprivation and his/her temporary guardian/representative objected to the request for deprivation. In all these cases, the person was partially deprived of legal capacity despite the fact that in three cases the requesting party explicitly demanded full deprivation. This points out the importance of good representation and active participation in the process, something very rarely found in the cases under review.

Formal objections to the procedure

Category/frequency	# of cases	% of cases
No objection / not mentioned	897	90.3%
Objection "out of precaution" ⁵⁸	47	4.7%
Objection by legal representative/temporary guardian	34	3.4%
Objection by the person	12	1.2%
Objection by both - legal representative/temporary guardian and the person	4	0.4%
Total	994	100%

Substantive Issues from the Case Law

Given that the crux of the problems in capacity deprivation arises from the substantive shortcomings of the procedure, it is important not to focus solely on procedural shortcomings. In this sense, the most evident concern is that justifications for decisions are generally weak or nonexistent. Therefore, in many cases it is unclear how the court reached its conclusion regarding the person's inability to look after his or her own rights and interests or the rights and interests of others, other than on the basis of diagnosis. We found few examples in which there is a direct relationship between the person's behaviour and a threat to his own rights and interests and those of others. This leads us to conclude that the courts view a psychosocial or intellectual disability to be sufficient justification for a person inability to take care of his rights and interests and those of others. This practice stands in clear and direct violation of the UN Convention on the Rights of People with Disabilities, but it also serves to underscore the general problematic attitudes of society towards people with disabilities.

⁵⁷ Whether a person even managed to establish visual contact with the judge deciding on the case was assessed by the existing information regarding the person's presence at the hearing. All decisions indicated which actors were present at the hearing. Where it was not explicitly stated that the person was present and it was not explicitly stated that judge was present at the examination, we concluded that the person was not seen by the judge.

⁵⁸ This can be understood only as a formal objection, where the representative is not providing any supporting argumentation. Objection "out of precaution" has no effect on the outcome of the process.

The role of medical experts is problematic as well. In many cases, the experts exceed their legal authority. For instance, in addition to providing reports and opinions regarding the person's mental state and capacity to reason, they provide conclusions or recommendations regarding the person's legal capacity. Similarly, in quite a few cases the experts suggest the complete and permanent divesting of legal capacity, which is problematic from two aspects: Firstly, any recommendation regarding divestment of the person's legal capacity falls outside of the expert's legal authority, and secondly, there is no basis in the law for permanently divesting someone of legal capacity, since the law provides for the possibility of reinstating legal capacity.

Extremely concerning is the fact that, with the exception of higher court case-load, we encountered not a single case in which the judge did not rule in accordance with the court experts' recommendations or in which the judge examined the experts' findings critically. Indeed, it would seem that the judges allow the medical experts to fully assess the merits of the case, while they themselves focus on its procedural aspects. This is a problem related to the role of court experts in general and their relationship with the court. The court hires experts in areas in which it lacks competency, yet it has the power not to accept their findings and opinions. The question arises on what ground the court might reject any findings in the area where it lacks competency. The following examination may provide some guidance.

Medical experts frequently cite a person's behaviour or appearance, which in no way should form the basis for depriving someone of legal capacity. By negatively describing a person's looks or assigning negative characteristics such as arrogance, lack of cooperation, rudeness, etc., the experts seem to want to strengthen their standpoint by devaluing the person as an equal member of a society. Whether such assessments should even be included in a one- to two-page court decision is highly debatable, since they indicate a prejudicial assessment of persons with psychosocial or intellectual disabilities. For example, the experts commonly use phrases such as "(the person) does not understand or comprehend anything" or "(the person) does not accept hospitalised treatment because of his (mental) condition." Surprisingly, in several cases the experts proposed long-term placement in a social care institution as "the most adequate form of placement". On the other hand, the experts' opinion never make it clear whether they attempted to employ alternative means of communication if a person was non-verbal or appeared not to understand them. Such serious shortcomings in the experts' opinions and the manner in which the information was obtained should be subject to increased scrutiny by the judges. The role of the judge must be to reject those expert findings that are influenced by prejudice towards persons with disabilities.

Finally, there is clear link between capacity deprivation and placement in a medical or social care institution. Persons whose guardian is employed by a Centre for Social Work or whose family members are unable or unwilling to provide care are commonly placed into a social care institution. If the person has or inherits any property, they have no say on what happens to it – the guardian and the centre for social work decide and dispose of it. The statistics on the institutionalisation of persons without legal capacity are worryingly high. In more than half (57%) of all cases reviewed, the person deprived of legal capacity was institutionalised either sometime during his lifetime or at the time of the procedure. Of those persons, at least 4% were hospitalised involuntarily.

It should be noted that this study looked at only one side of the issue of legal capacity – court procedures – and did not examine procedural and substantive issues that arise from the administrative procedure related to guardianship assignment and monitoring. We thus know little about what actually happens to the rights and property of persons under guardianship. As this is a truly broad topic, and certainly one of great importance, such an analysis should be the subject of a separate research study.

**Recognizing the importance of the legal capacity of persons with disabilities:
The practice of the higher courts in Serbia within the current legal framework.**

The above-described shortcomings of the work of the municipal courts in deciding on the legal capacity of persons with disabilities have been recognized by some of the higher courts in their reasoning of rulings on appeals of first-instance court decisions. While the higher courts do not analyse whether the experts' findings and opinions are based solely on the medical model of disability or whether they are influenced by prejudicial views towards persons with intellectual and psychosocial disabilities, they do seem to recognize the failure of the municipal courts to implement procedural rules and safeguards.

For example, the Higher Court in Subotica states: "The sole existence of the illness without the existence of acts that might directly endanger the person's rights or the rights and interests of others is not a legal basis for partial deprivation of legal capacity [...] The municipal court has established that respondent's illness involves a mental disorder, bizarre delusions that everybody is against him, and that he interprets all events wrongly. It [the municipal court] has established that his paranoia is directed against his son because of the conflicts that arise between them. It does not follow that he might undertake any act that might leave him without material means, except that the argument with his son caused him to demand that he should not manage his pension in the future. According to the standpoint of this court, this gesture on the part of the respondent cannot, on the basis of the existing evidence, be brought into a causal relationship with the respondent's illness, which was correctly established in detail by the first-instance court on the basis of the experts' findings and opinion. Therefore, it becomes necessary to establish the existence of specific acts by the respondent from which we may conclude that he, as a consequence of his illness, endangers his rights and interests or the rights and interests of others persons."

The Higher Court in Pancevo concludes: "The task of the medical experts is to provide, on the basis of existing medical documentation, findings and an opinion on the mental state and capability of a person to reason and nothing more. In this case, however, the experts provided opinions regarding the fact that the respondent allegedly easily disposes of land. The question arises as to what information they used to make this statement."

The Higher Court in Pirot notes that the examination by the medical experts was not conducted in the presence of a judge, despite the fact that it was not held in a medical institution. Furthermore, it notes another violation of procedure: "...the present decision does not determine which legal actions the respondent may or may not undertake following his partial deprivation of legal capacity."

The Higher Court in Sremska Mitrovica concludes that the law was violated because the respondent was not present nor heard at the hearing, although no circumstances existed that might allow the court to waive hearing the respondent. Likewise, the court found a violation in that "the examination was conducted by two neuro-psychiatrists, but not conducted in the presence of a judge."

Conclusion

Article 12 of the UN CRPD mandates that persons with disabilities receive support, but deprivation of legal capacity does not afford any support. In Serbia, the legal framework affords “protection” in a paternalistic fashion, an approach abandoned by the international standards on the human rights of persons with disabilities. As one can imagine, this “protection” is often abused or misused by those given the authority to protect the interests of the vulnerable. The current legal framework for legal capacity in Serbia is not adequate for a procedure of such high importance, in which a person is deprived of almost all of their rights. On a similar note, the above findings on judicial practice warrant a serious consideration of systematic change in the field of legal capacity. This study has unambiguously demonstrated that the procedure by which a person is deprived of all rights fails to ensure equality of arms (procedural equality of both parties), with weak safeguards and no practical possibility for revoking the status of legal incapacity. The courts do not act as guardians of justice, but yield to the superficial assessments of medical experts who fail to offer any deeper insight into a person’s needs, and frequently offer an insight that is solely medical and strongly prejudicial. In the end, we may state that legal capacity deprivation is immensely unjust, and that persons are made more vulnerable by the loss of their rights without receiving the necessary support from the system.

Recommendations:

- Gear the law and public policy towards creating diverse options so that the opportunity for growth and development is afforded to all persons with disabilities including opportunities for restoring or sparking the capacity to make decisions;
- Shift the approach from the medical to the social model of disability in the field of legal capacity by devising a new legislative framework;
- Amend the Family Law and Law on Non-Contentious Proceedings so that instead of being deprived of legal capacity, persons with intellectual or other disabilities are given adequate support (such as: advance planning, the right to accessible information, reasonable accommodations, legal support, supported decision-making, facilitated decision-making and co-decision-making) when making decisions that affect their life;
- Amend all other laws that restrict the rights of persons without legal capacity;
- Until a comprehensive legal reform is made, court rulings should limit persons’ legal capacity to the least possible extent and should work towards developing an individual approach to assessing the challenges faced by disabled people:
 - > Use existing procedural guarantees and hear the person, be present at the experts’ examinations of persons, make efforts to communicate with persons in simple language or use other means of communication if persons are non-verbal, and establish visual contact with every person;
 - > Pay special attention to the quality of legal representation of persons before the court, and assess whether a conflict of interest may exist between a person and their temporary guardian;
 - > Use partial deprivation instead of full deprivation in order to pay more attention to each individual case; evaluate capabilities of each individual person and limit legal capacity only in those areas in which incapacity is established without a doubt and always as a last resort;
 - > Provide detailed reasoning of the grounds for depriving someone of legal capacity;
 - > Use statutory authority to initiate ex officio proceedings for reinstating legal capacity, and establish a reporting system for all people who have been deprived of legal capacity so that court decisions are periodically reviewed;
 - > Act on requests for the reinstatement of legal capacity which are lodged by the persons themselves and/or the person’s guardian;
 - > Critically examine the reports and opinions of court medical experts.

LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

Legal and Policy Analysis

Serbia's constitution does not address the right of persons with disabilities to live in the community. Nevertheless, Article 69 (which addresses social protection) in Serbia states that social protection is provided according to the principles of social justice, humanity and respect of human dignity, and that "invalids"⁵⁹ are entitled to special protection in accordance with the law.

New Principles in Social Protection

The main regulations for giving persons with disabilities the right to community living are contained in the new Law on Social Protection.⁶⁰ Article 4 of this law states that each individual has the right to the social protection indispensable for overcoming social and life barriers and enabling conditions for satisfying one's basic life needs. Article 5 defines social services as "activities of support and assistance to users and their families for improving or retaining their quality of life, removing or mitigating the risk of negative life conditions, and creating the conditions for living independently within the community" (emphasis added).

The principles of this law are in line with the concepts of community living and the social inclusion of vulnerable persons, including persons with intellectual disabilities. For instance, the principle of least restrictive environment mandates that social services be provided primarily in a direct and least restrictive environment, while choosing those services that enable the user to remain in his or her community.⁶¹ The law further introduces the principle of accessibility (physical, geographical and economical) and individual approach.⁶² As the law does not couple these principles directly with the operative legal provisions that regulate the provision of social services, it is not evident how these principles will be translated in practice. A system of rulebooks under the law is expected to regulate all issues more specifically.

Institutional Placement Under the Law

With the new Law on Social Protection, institutional placement became only one form of social services. Institutional placement is provided to users for whom family stay, community services or family placement either cannot be provided, or are not in their best interest.⁶³ Children younger than three years of age cannot be placed in institutional care except in cases of particularly justified reasons, and children cannot spend more than two months there, except with the approval of the relevant ministry.⁶⁴ The ambiguity of the expression "particularly justified reasons" leaves much room for arbitrary assessments of a child's need for institutional care, and thus requires particular attention and scrutiny.

The article on institutional placement must be read in conjunction with the right to participate in decision-making on the use of social services and the right to a free choice of services.⁶⁵ The relevant provisions state that users have a right to participate in an assessment of their own situation and needs and to decide whether to accept services – based on the receipt of timely and necessary information. This is huge step forward, to a situation in which social services are now oriented towards

⁵⁹ Most legal terminology referring to persons with disabilities, especially persons with psychosocial or intellectual disabilities, is archaic and politically incorrect. In most cases, the authors have replaced such language with non-stigmatising terminology. In other cases, outdated terminology is placed in quotation marks.

⁶⁰ Official Gazette of the Republic of Serbia, No.24/2011, Law of Social Protection.

⁶¹ Ibid., Article 27.

⁶² Ibid., Article 33.

⁶³ Ibid., Article 52, paragraph 1.

⁶⁴ Ibid., Article 52, paragraph 2 and 3.

⁶⁵ Ibid., Article 35 and 36.

the user. Nevertheless, the right to participate and freedom of choice as guaranteed by the law do not apply to persons without legal capacity, since by law these rights are exercised by the legal guardian.⁶⁶

From the legislation, it appears as if there was an attempt at protecting legally incapacitated persons from their guardians' wanting to place them in institutions. Article 78 states that direct contracting of services⁶⁷ cannot be done for residential placement of persons without legal capacity – instead, a referral by the intermediary centre for social work or decision of the court is needed. In order to make this provision operational, we need to strengthen centres for social work, in particular by finding ways of issuing referral for services in non-restrictive environments.

Family Support as a Way of Preventing Institutionalisation

Under the Labour Law, one of the parents or guardians of a child who needs special care because of high degree of psychophysical “defect” has the right to full-time paid leave or to half-time work until the child reaches five years of age.⁶⁸ Similarly, parents may exercise their right to material assistance if they are the sole caregiver for a child with disabilities in a way that prevents them from being employed.⁶⁹

The new Law on Social Protection introduced the possibility of financial support for family members. It states that parents who are not employed, who have been directly caring for a child, and who have exercised their right to an increased caregiver allowance for at least 15 years may claim lifelong income in the amount equal to the lowest pension when they meet the general age requirements for receiving a pension if they have not already claimed their pension.⁷⁰ The reasoning behind this provision of the law is that elderly parents who are left without any income are under heightened risk of institutionalising their now-adult child. However, the value of this basic social security support for the elderly is highly limited (due to the multiple conditions and the small financial amount), and it does little to prevent institutionalisation.

In comparison to its failure to provide support for families, the law provides substantive support for foster care and foster parents. The development of foster care is certainly a significant step towards de-institutionalisation, but the unequal treatment by the law arguably goes beyond the necessary affirmative action measures, i.e., it does more than merely define incentives for foster parents. Foster parents receive not only increased monthly compensation for caring for a child with developmental difficulties and additional financial assistance for all child-related expenses,⁷¹ but there exist other valuable services that are currently provided only to foster and adoptive parents. The Centre for Family Placement and Adoption promotes the preparation, assessment and education of future foster parents and adoptive parents, provides support for foster parents, adoptive parents, and families engaged in family placement.⁷² Since there is no place/institution where families with children with disabilities can receive training and counselling, this service should become available to biological parents as well.

New Community-based Services, Financing and Standards

Article 40 of the Law on Social Protection provides a list of social services. These are grouped into: assessment and planning services, day services within the community, independent living support services, counselling and socio-educational services, and accommodation services including placement into residential institutions.

⁶⁶ Ibid., Article 35, paragraph 2: “Without the consent of a user respectively their legal representative...”
[Bez pristanka korisnika odnosno njegovog zakonskog zastupnika...]

⁶⁷ Ibid., Article 77 regulates direct contracting of services.

⁶⁸ Official Gazette of the Republic of Serbia No. 24/05, 61/05 and 54/2009, Labour Law, Article 96, paragraph 1.

⁶⁹ Law on Social Protection, Article 83, paragraph 4.

⁷⁰ Ibid., Article 94, paragraph 6 (emphasis added).

⁷¹ Official Gazette of the Republic of Serbia No. 15/92, 100/93, 12/94/ 51/97, 70/2003, 99/2004, 100/2004, 25/2005, 77/2005, 60/2006 and 8/2011, Rulebook on criteria and measures for establishing prices of services in the field of social protection which are financed by the Republic, Article 10a and 10b.

⁷² Law on Social Protection, Article 131.

Specific services that fall under these five groups are:

- assessment of condition, needs and strengths of and risks to users and other significant persons within their surroundings; assessment of guardian, foster parent or adoptive parent; development of an individual or family plan for the provision of services; legal protection measures and other assessments and plans;
- day-care stay, help in the household, drop-in centre, other services that promote the individual remaining within the family and direct surroundings;
- supported living, personal assistance, training for independent living, other types of support necessary for active participation in society;
- intensive support services for families in crisis; counselling and support for parents, foster parents and adoptive parents; support for families caring for children or grown family members with “developmental difficulties”; preservation of family relations and reuniting families; counselling and support in cases of violence; family therapy, mediation, SOS phone-lines, and other counselling and educative services;
- placement among relatives, within a foster or other family, residential placement, placement in a drop-in centre and other types of placement.

One positive aspect of the law is that it recognizes that the quality of care and services is a crucial for their provision. Therefore, each of the above-listed type services requires a defined set of standards and accreditation.

The law introduces procedures for the accreditation of programs and training sessions for service providers. Previously, institutions were seen as the only social service for persons with psychosocial and intellectual disabilities. As a result, the standards were contained in two rulebooks focused only on standards for institutions for adults with psychosocial and intellectual disabilities⁷³ and standards for institutions for disabled children.⁷⁴ These rulebooks prescribe the necessary number of professional and other staff in institutions,⁷⁵ and lay down requirements for the school's physical space, equipment, food, wardrobe, personal belongings, common consumption, etc. The rulebooks do not address the treatment of and work with the institution's residents. The accreditation includes the development of standards for each particular service recognized by the law. These should relate not only to the operational standards contained in these two mentioned rulebooks, but should also address the substance of service provision such as individual approach, the user's participation, etc.

The responsibilities for the financing and provision of social services, including community-based services, are defined in section XIV of the Law on Social Protection. Specifically, it lists which particular services are the responsibility of which levels of government. Most services are the responsibility of local governments, which is logical in that local authorities are the most familiar with the needs of the people in their community. Central and regional governments finance the largest expenditures such as social benefits and institutions. One positive factor is that the central and regional governments are also responsible for financing new supported living services for persons with disabilities in those counties whose index of development is below the nationwide average. Also, the law envisions allocated transfers for social services for these localities. These transfers are also foreseen for the transformation of residential institutions and for innovative local services and social services that are of significance to the country as a whole.

Future Direction of De-institutionalisation in Law and Policy

The future of residential institutions for persons with disabilities in Serbia remains unclear. The law

⁷³ Official Gazette of the Republic of Serbia, No. 88/93 and 53/2005, Rulebook on the Conditions for Working with Adults with Developmental Disorders, Mental Illness, or Invalid Persons, Including Operating Standards for Social Care Institutions.

⁷⁴ Official Gazette of the Republic of Serbia, No. 88/1993, Rulebook on the Conditions for Working with Children and Youth with Developmental Disorders, Including Operating Standards for Social Care Institutions.

⁷⁵ These standards prescribed less clothing, fewer tools and equipment, and a lower number of professional staff for the most disabled children as compared to children with less serious disabilities (Articles 21, 23 and 26 of the Rulebook on the Conditions for Working with Children and Youth with Developmental Disorders, Including Operating Standards for Social Care Institutions).

defines the capacity for social care institutions as 100 adults and 50 children (Article 54). Institutions have a maximum of three years to adjust their capacity to this standard (including all other prescribed standards as well).⁷⁶ A ministerial order that used to prohibit the placement of children under the age of three into institutions except in unusual cases and with the approval of the relevant ministry has been turned into law, thus giving it statutory strength. Whether the exception to the rule will remain an exception in practice is yet to be seen. It is highly alarming, however, that Article 10 and Article 113 provide for the establishment of new institutions within the social care without exception, which implicitly includes residential institutions for persons with intellectual and psychosocial disabilities.

National policy seems to express a general tendency towards de-institutionalisation, but there are no plans for ending institutional placement. In 2007, the Serbian government adopted the Strategy for Improving the Position of Persons with Disabilities.⁷⁷ This Strategy defines the medium term activities related to advancing the position of persons with disabilities. The strategy's goals are set for the 2007-2015 period, with action plans to be developed every two years.⁷⁸ De-institutionalisation or the transformation of institutional care is not included in this strategy's general goals,⁷⁹ but is mentioned in Measure 4 of Specific Objective 5: To improve the service and support system for users in accordance to their needs, which explicitly refers to de-institutionalisation and states that social, health and other services for persons with disabilities must fully respect the principle of accessibility of services within the local community "with full implementation of the process of de-institutionalisation." Similar wording can be found in Measure 1 of Specific Objective 6: To strengthen the families of persons with disabilities by providing adequate support for appropriate services helping to integration persons with disabilities into the community. At the same time, de-institutionalisation is not defined in any governmental documents, nor are any steps or deadlines foreseen.

Another document that is relevant to the reform of institutional care is the Strategy for Development of Social Protection,⁸⁰ which realistically identifies all the shortcomings of the social protection system, in particular as regards persons with disabilities. Its Specific Goal 2 is the realization of a network of community services. This strategy's goals and objectives were mostly addressed by the enactment of the new Law on Social Protection. It also represents the most detailed account of the future plans for de-institutionalisation. Under its specific goals, the strategy defines the direction of residential services reform for children and adults with disabilities. It states that the current network of institutions should be questioned together with the services and quality of current institutional placement.⁸¹ When it comes to children's institutions, "questioning implies transformation through the development of additional types of services and by educating staff in new types of work."⁸² By developing foster care and adoption, these institutions' capacities will be decreased. Residential capacities for adult users must be redirected towards family placement and smaller-capacity institutions that recreate as close as possible the user's natural surroundings. The standards also call for an increase in the type, quantity and quality of services, for the creation of medium-term plans, and for transformation plans for each institution in question. The strategy concludes that, "for a certain number of users of the social care system, residential services are indispensable." This appears to be the central premise on which plans for de-institutionalisation of children with disabilities are developed. It should be noted that practical experience from many countries that have closed children's institutions shows that this assumption is without any basis.

When it comes to the capacity of institutions and specific policies, it is useful to look at the Decision on the Network of Institutions of Social Care for the Residential Placement of Users.⁸³ This decision establishes the capacities for all social care institutions, which must: a) align their statutes with the decision and b) implement the decision by aligning their number of users and staff with the prescribed capacities. According to the latest decision, the total number of children with disabilities in institutions for children with disabilities must be fewer than 860 by 1 January, 2014. As for adults with intellectual and psychosocial disabilities placed in institutions, their number by the same date should total no more than 4,457, with an additional 300 persons in institutions for adults with physical or sensory disabilities. Still, these figures cannot be taken as the maximum number of institutionalised persons

⁷⁶ Ibid., Article 223 (2). All service providers must submit a licensing request within 3 years of the date of the standards' creation.

⁷⁷ Official Gazette of the Republic of Serbia, No. 1/2007, Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia.

⁷⁸ While several municipalities and towns have adopted local action plans for persons with disabilities, at the moment of writing, no national action plan has been adopted. ----> Opposite page: ^{79, 80, 81? 82, 83}

with disabilities, since institutions for children without parental care or for the elderly also house children and persons with disabilities.

Analysis of Practice

Analysing Government Data on Institutions for Persons with Intellectual Disabilities

The Serbian social care system includes six institutions for children and youth with intellectual disabilities and autism, seven institutions for adults with intellectual disabilities, three institutions for adults with physical and/or sensory disabilities, and five institutions for adults with psychosocial disabilities. However, this classification does not necessarily mean that a particular institution's residents are exclusively persons whose disability and age correspond to the institution's purpose. In other words, young persons with disabilities are also placed in institutions for the elderly, children and youth with intellectual disabilities are placed in institutions for adults with intellectual disabilities, and adults with intellectual disabilities are often placed in social institutions for persons with psychosocial disabilities.⁸⁴

Number of persons with disabilities in social care institutions for persons with disabilities, 2010

Institutions/Disability	Intellectual disabilities	Autism	Other disability	Total number
for children and youth with intellectual disabilities and autism	1,257	6	247	1,510
for adults with intellectual disabilities	1,503	1	154	1,658
for adults with physical and/or sensory disabilities	19	0	234	253
for adults with psychosocial disabilities	406	0	1,980	2,386
Total	3,185	7	2,615	5,807

The above government-published data⁸⁵ show that persons with intellectual disabilities are placed in all forms of social care institutions. In reality, however, the number of users with some sort of intellectual disability is higher than portrayed in the table's categories. Firstly, the government report does not include one institution for children,⁸⁶ and secondly the structure of disabilities includes the ambiguous category of 'combined' or 'multiple' disability – which can include persons with intellectual

⁷⁹ Mainstreaming of disabilities into general development plans, developing effective legal protection with implementation of prevention plans, developing policy measures and programs in education, employment, work and housing, ensuring that persons with disabilities can access the built environment, transportation, communications and public services.

⁸⁰ Official Gazette of the Republic of Serbia, No. 108/2005, 71/05, Strategy for Development of Social Protection.

⁸¹ Ibid., 38.

⁸² Ibid., 38.

⁸³ Official Gazette of the Republic of Serbia, No. 98/2010, Decision on the Network of Institutions of Social Care for Residential Placement of Users.

⁸⁴ Strategy for Development of Social Protection, page 8.

⁸⁵ Report on the Work of Social Protection Institutions for Persons with Disabilities, Belgrade, May 2011.
<http://www.zavodsz.gov.rs/PDF/naslovna/god-izvestavanja/OSI.pdf>.

⁸⁶ The government report does not provide any data for institution the Zvečanska Home for Infants, Children and Youth in Belgrade, meaning that there is data for only six out of seven institutions.

⁸⁷ Special Report of the Ombudsman on Inspections Conducted at Social Care Homes for the Elderly in 2010.
<http://www.ombudsman.rs/index.php/lang-sr/izvestaji/posebni-izvestaji/2108--2010>.

disabilities as well. The data for institutions for the elderly has not been analysed, but according to the ombudsman's office, these institutions are also home to a number of younger and older persons with intellectual disabilities.⁸⁷

Compared to the total population of Serbia and an estimate of the number of persons with intellectual disabilities in Serbia (2% or 150,000)⁸⁸, we can state that the number of institutionalised children and adults with intellectual disabilities is relatively low (about 3,200 reported). Another question arises: How many persons with intellectual disabilities including autism who are living within their communities? The government has no estimate of this number, nor any means of attaining it. The 2011 census may offer an initial indication of these figures.

In examining the reasons for leaving institutional care, the government report states there was no significant change over previous years – the dominant reason still remains the user's death, even at institutions for children and youth.⁸⁹

Reasons for leaving social care institutions for persons with disabilities, 2010

Institutions/Reason	Death %	N	Transfer to another institution	Transfer to biological, foster or other family or supported living (DI)	Other - unknown	Number of users who left institution
for children and youth with intellectual disabilities and autism	39.8	35	28.4%	30.7%	1.1%	88
for adults with intellectual disabilities	71	68	22%	6%	1%	96
for adults with physical and/or sensory disabilities	71	39	11%	9%	9%	55
for adults with psychosocial disabilities	87	135	4.5%	8%	0.5%	155

In 2010, there were 277 deaths at 20 social care institutions. According to the above data (which was collected and published by government offices), the mortality rate in institutional care is almost 48 out of 1,000. By comparison, according to the Statistical Office of the Republic of Serbia the 2010 mortality rate in Serbia was 14.2 per 1,000 inhabitants. This discrepancy gives rise to great concerns and raises a very important question: Is the right to life in Serbian institutions for persons with disabilities properly protected and ensured? Is it possible that the mere presence of a disability justifies a mortality rate that is more than triple the country's average mortality rate? This issue is certainly something that needs to be scrutinized by the authorities. Out of 277 deaths, only six were reported as violent (five suicides and one murder) and three were of unknown cause. The government reports

⁸⁸ While there is no absolute count of people with intellectual disabilities around the world, in this report we use the average estimates normally used by researchers and demographers in the field – 2.0% of the global population.

⁸⁹ Report on the Work of Social Protection Institutions for Persons with Disabilities, page 37.

state that most deaths (268 out of 277) were from illness or were natural deaths, but fail to give further information. This raises the question as to whether any further inquiry is made into causes of deaths that are perceived to be non-violent.

Deaths at social care institutions for persons with disabilities, 2010

Institutions/Deaths	Illness or natural death	Murder	Suicide	Unknown	Total deaths
for children and youth with intellectual disabilities and autism	35	0	0	0	35
for adults with intellectual disabilities	67	1	0	0	68
for adults with physical and/or sensory disabilities	38	0	1	0	39
for adults with psychosocial disabilities	128	0	4	3	135

The data in the government report point to the possibility that serious overcrowding and lack of privacy persist at all institutions. With the exception of institutions for persons with psychosocial disabilities, the number of persons living at social care institutions does not exceed the total capacity defined by the decision.⁹⁰ Nevertheless, this information tells us little about the actual situation at each individual institution – not only because the data is grouped by type of institution, but more importantly because capacity is determined on the basis of the actual number of persons living there, not on the basis of standards for the adequate personal space for residents. As a result, institutions and particular wards within institutions may be at the official capacity limit or below even though the residents might be living in multi-bed rooms with a complete lack of personal space.⁹¹

Most rooms at institutions are multi-bed rooms containing more than three beds (the total number of beds in single, double and triple-bed rooms is 850; the total number of beds in rooms containing more than three beds is 4,941).⁹² This shows that institutional care in Serbia is predominantly of a dormitory style, which is not conducive to a home environment. Long-term living in a room with three or more other persons certainly violates an individual's privacy.

Capacity by number of beds per room

Institutions/Number of beds	# of residents in single bed rooms	# of residents in double bed rooms	# of residents triple bed rooms	# of residents in 4+ bed rooms
for children and youth with intellectual disabilities and autism	3	32	39	1,392
for adults with intellectual disabilities	7	86	189	1,450
for adults with physical and/or sensory disabilities	11	94	18	177

⁹⁰ Report on the Work of Social Protection Institutions for Persons with Disabilities, page 28. The number of users at stay in institutions of social care for persons with psychosocial disabilities in 2010 was 2,386 while the total capacity was 2,293.

⁹¹ Helsinki Committee for Human Rights in Serbia: People on the Margins (Part 4): Social care institutions for children and adults with psychosocial disabilities and persons with mental disorders, page 17. In Sremčica, the Helsinki Committee found a child pavilion housing as many as 14 children per room (2009). Accessed December 2011. <http://www.helsinki.org.rs/doc/People%20On%20The%20Margins%20-%204.pdf>.

⁹² Report on the Work of Social Protection Institutions for Persons with Disabilities, analysis of four graphs on pages 5, 12, 20 and 28.

Institutions/Number of beds	# of residents in single bed rooms	# of residents in double bed rooms	# of residents triple bed rooms	# of residents in 4+ bed rooms
for adults with psychosocial disabilities	6	140	225	1,922

The government report identifies different circumstances leading to the institutionalisation of disabled children as compared to disabled adults. For children, the list of possible reasons for institutionalisation is as follows: deceased parents, unknown parents, parents fully or partially deprived of parental rights, parents deprived of legal capacity, parents prevented from exercising parental rights, parents unable to meet the child's needs, and inadequate parental care. In a majority of cases, the parents were either prevented from exercising their parental rights or they were unable to meet the child's needs.⁹³ For adults, the leading reasons for institutionalisation are: no close relatives, the family is not prepared to look after the person, socio-economic vulnerability, and inadequate family care.

Reasons for institutionalisation for persons with disabilities, 2010

Institutions/Reasons	No close relatives	Family not prepared to look after person	Socio-economic vulnerability	Inadequate family care	Other reasons
for adults with intellectual disabilities (only for residents above 18)	36%	50%	5%	5%	4% (3% personal choice)
for adults with physical and/or sensory disabilities	33%	32%	20%	4%	11% (4% personal choice)
for adults with psychosocial disabilities	16%	26%	3%	5%	50% (49% socio-health indications)

While some of these categories are overly ambiguous (such as the definition of parents or family not being 'willing to look after' a disabled person), they also fail to answer why the state has determined that placement in a residential institution is the only possible option for the person. If an adult has no close relatives to support him or has no sufficient means, this should not be used to justify the state's failure to help them remain in their homes in the community. The data also indicate that it is still acceptable in Serbia to "not be prepared" to look after a person with a disability.

The statistics related to the length of stay is discouraging: only 4% of child residents are in institutional placement less than 12 months, while only 7% of residents at institutions for adults with intellectual disabilities are there for less than 12 months.⁹⁴ According to statistics, 94% of children with intellectual disabilities and 93% of adults with intellectual disabilities placed in institutions are there longer than one year. This underscores the notion that, once a person enters institutional care, he or she will stay there for a long time.

Human Rights at Institutions

Information about the daily life of persons with disabilities in institutional care in Serbia would help to reveal the degree to which their human rights are respected or violated. Such information, however, cannot be found in the government reports. The report on the work of institutions briefly states that

⁹³ Ibid., 7.

⁹⁴ Ibid., 8 and 15.

⁹⁵ Ibid., 37.

⁹⁶ Strategy for Development of Social Protection, page 8 and 38.

⁹⁷ Ibid., 8.

programs for promoting residents' rehabilitation and independence, as well as programs contributing to their greater social inclusion, are not sufficient.⁹⁵ On this note, the Strategy for the Development of Social Protection also states that institutions do not have adequate programs, that the quality of services is uneven, and that the institutions do not provide adequate support for preserving users' potential and improving their quality of life.⁹⁶ Residents commonly live in varying degrees of social isolation.⁹⁷

A myriad of issues need to be examined further in order to be able to come to conclusions on how, or whether, the rights of institutionalised persons with intellectual disabilities are being respected. A non-exhaustive list of issues for examination includes:

- Receipt of adequate medical protection, protection from undue medical treatments and/or interventions;
- Receipt of adequate education for children (and work for adults);
- Protection from violence and abuse, both from other residents and from the staff;
- Regular contact with family and important others from outside the institution;
- The right to privacy and intimate relations;
- Free movement on the premises and outside of the institution;
- The right to make decisions about personal belongings, finances, and free time, and to exercise control over their lives;
- Equal opportunities and treatment for all residents, with regard to their individual personal characteristics (such as gender, age, type and degree of disability, nationality and religion).

None of this information can be found publicly in state monitoring reports, which apparently do not explore the human rights of persons with disabilities living in institutional care. Because of its limited capacity, the ombudsperson's mechanism for the prevention of torture and mistreatment has held only one preventive visit to a social care institution for persons with disabilities since being established in 2008.⁹⁸ The Serbian National Preventive Mechanism (NPM) was formed in 2011 with a significant delay. It called on the Ombudsman to act in the role of NPM, in cooperation with civil society organizations whose mission is to improve and protect human rights and freedoms.⁹⁹ Independent monitoring by civil society organizations also occurs only sporadically and is not encouraged by the authorities.¹⁰⁰

In November 2007, Mental Disability Rights International published its report "Torment not Treatment: Serbia's Segregation and Abuse of Children and People with Disabilities,"¹⁰¹ in which it detailed abuse at institutions, segregation from society and discrimination, and violations of international conventions. The report resulted in a large amount of attention by the national and international community and pushed for reform in this field. In 2009, the Serbian Helsinki Committee (SHC) conducted the most recent monitoring session at four state-run institutions. Unfortunately, the findings were not much different than in 2007.

MDRI and SHC identified numerous human rights violations and situations that are not conducive to the well being of people in institutional care. We here name just a few, primarily in order to emphasize those issues that are critical for achieving a shift in attitudes and behaviour towards persons with disabilities. Issues that urgently need to be addressed include segregation, overmedication, lack of understanding of residents' needs, and unequal treatment of residents. We must emphasize that this shift is not only immediately necessary but is also not costly.

⁹⁸ Ombudsman: Report on Inspection of Residential Conditions and Respect for Users' Rights, with a Specific Focus on Socio-Psychological and Health Protection at Special Institutions for Children and Youth, Dr. Nikola Šumenković in Starnica, 9 June 2009. Accessed 6 January 2012. http://www.ombudsman.rs/index.php/lang-sr_YU/izvestaji/posebnii-izvestaji/501--q-q-

⁹⁹ Official Gazette of the Republic of Serbia, Nr. 16/05, 2/06, and 7/2011, Zakon o ratifikaciji Opcionog protokola uz Konvenciju protiv torture i drugih surovih, neljudskih ili ponižavajućih kazni i postupaka, Article 2a. Note: the Optional Protocol to the Convention against Torture requires that state parties form the National Preventive Mechanism (NPM) regularly examine the treatment of persons deprived of liberty.

¹⁰⁰ Authorities Denied Access to Social Care Institutions for Civil Society Organizations, Human Rights Watch World Report 2011, 466. <http://www.hrw.org/world-report-2011>.

¹⁰¹ Mental Disability Rights International, November 2007. <http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/Serbia-rep-english.pdf>.

¹⁰² Helsinki Committee for Human Rights in Serbia: People on the Margins (Part 4): Social care institutions for children and adults with psychosocial disabilities and persons with mental disorders, page 3. Accessed December 2011. <http://www.helsinki.org.rs/doc/People%20On%20The%20Margins%20-%204.pdf>.

¹⁰³ Ibid., 14.

The SHC team found overmedication of residents at all visited institutions.¹⁰² Chemical restraint is a frequent systematic practice for the convenience of the staff, but is detrimental to residents' human rights. Another common finding was that the staff failed to recognize and respond to the needs of individual residents. For example, medical staff was unable to explain sudden changes in residents' behaviour such as outbursts of aggressiveness or agitation.¹⁰³ Non-medical staff was reportedly not capable of understanding how the living conditions at the institution affect residents, and so misinterpreted the residents' actions (such as attempts at escape) as features of their condition (disability and problematic behaviour).¹⁰⁴

Moreover, the researchers encountered an apparent inequality in the treatment of residents according to their level of disability or perceived problematic behaviour. Those residents whom staff perceived as being problematic were purposefully excluded from activities and programs,¹⁰⁵ while those with severe psychosocial and/or physical disabilities were neglected to the point that staff did not even help them get out bed. Yana Buhrer-Tavanier, an investigative journalist who also conducted visits to several institutions in Serbia in 2009, describes this phenomenon as "parallel universes" where all activities and programs are directed at those residents that are easiest to work with, while those who are the most in need of assistance get the least of it.¹⁰⁶ Existing policies and approaches to working with clients perpetuate this lack of assistance to the most disabled persons, and are not only unjust but stand in clear violation of the CRPD guarantees that apply equally to all disabled persons, regardless of the type and level of their disability.

Financing and Investments

Institutions are financed from a number of sources. The main financing comes from the Ministry of Labour and Social Policy (MLSP), while other contributors are the Ministry of Health, municipal governments, national and foreign donors and, if the institution is situated in northern autonomous province of Vojvodina, the Provincial Secretariat of Social Policy and Demographics. Institutions possess two bank accounts, one of which is strictly reserved for budgeted costs (payments per user, staff and management salaries, other operating costs), while the other is for various donations and expenses incurred on an irregular basis. Most homes are also partly financed from their own sources of income such as earnings from agricultural or animal farms and the sale of products and crafts made by residents.

Following the democratic changes in Serbia after 2000, massive amounts of humanitarian aid were used as emergency aid for renovating institutions for children and adults with disabilities with life-threatening conditions. To this day, the exact amount invested remains unknown, although a 2003 letter of gratitude by the MLSP to the donors states that donations were used for renovating institutions or increasing their capacities, and for the purchase of food, medicine, hygienic supplies, energy, vehicles, furniture, tools and aids, clothing, shoes, school kits, books and vacations for children.¹⁰⁷

After this period, the government of Serbia began articulating broader policies that implicated the social inclusion of institutionalised children.¹⁰⁸ This reform of children's care was not followed by any redistribution of financing from an institutional to a community-based system of care. The Ministry reports that in the four years from 2004-2007 the state invested a total of approximately RSD 800 million (EUR 8 million) in all institutions under the authority of the MLSP.¹⁰⁹ Over the subsequent period from 2008-2010, the amount of state investment was close to RSD 384.4 million (about EUR

¹⁰⁴ Ibid., 25.

¹⁰⁵ Ibid., 21.

¹⁰⁶ Buhrer Tavanier, Yana. 2009. Dumping Grounds for People. Accessed 6 January 2012. <http://dumpinggroundsforpeople.wordpress.com/read-the-investigation/full-length-investigation/>.

¹⁰⁷ LifeLine website: Press Clipping (from Vreme): Expression of Gratitude of the Ministry for Social Policy to HRH Crown Princess Katherine Foundation (20 March 2003). Accessed 6 January 2012. http://www.royalfamily.org/press/press-det/stampa-zahvalnica_yu.htm.

¹⁰⁸ Most relevant for transition to community care were: National Action Plan for Children of 2004, Strategy for Development of Social Protection of 2005 and Strategy for Improvement of the Position of Persons with Disabilities of 2006.

¹⁰⁹ Report of the Ministry of Labour and Social Policy on the conditions in residential institutions for children, adults and elderly persons with special needs, 2007, page 10. Accessed 6 January 2012. <http://www.minrzs.gov.rs/cms/yy/propisi/briga-o-porodici-i-socijalna-zastita>.

3.8 million).¹¹⁰ It is important to note that these funds are investments in addition to the regular monthly contributions from the state budget for covering regular operating expenses. Investments were several times greater in 2010 than in the previous two years.

Investment into institutions¹¹¹

Total investment - year	Investment (in RSD)	Equipment (in RSD)	Total (in RSD)
2008	81,603,395	15,945,851	97,549,246
2009	37,707,858	22,715,390	60,423,248
2010	196,772,438	29,641,335	226,413,773
TOTAL	316,083,691	68,302,576	384,386,267

As for the financing of community care, there is no overview of this type of investment. Community care is financed by project, based on regular calls for proposals issued by the MLSP and ad hoc calls by foreign donors. Most of these calls are directed at general disability or human rights associations, and it is difficult to assess the amount of funding that was directed specifically at the de-institutionalisation or the prevention of de-institutionalisation of persons with intellectual disabilities. Another factor that makes an assessment more difficult is the government's tendency to call new services offered by institutions on the institution's premises "community services". For example, a government report asserts that EUR 3 million was invested into adapting part of an institution for children without parental care in order to develop services for preventing the institutionalisation of disabled children, and to raise the standard of living of institutionalised children with disabilities.¹¹² Despite the lack of methodology for tracking the progress of community development and the ambiguities in the understanding of "community services", several dominant practices in funding may be identified with certainty.

The first such practice is that community care and the de-institutionalisation of disabled children received much attention (albeit with uncertain results), while the needs of adults with intellectual disabilities have so far been neglected. This may change with the EUR 2 million investment of the EU's IPA 2009 program. The project "Enhancing the Position of Residents in Residential Care Institutions for Persons with Mental Disability and Mental Illness and the Creation of Conditions for their Social Inclusion in the Local Community" aims to prepare and implement transformation plans for residential and psychiatric institutions for adults, as well as to develop a plan for cross-sectoral community-based social and health services. Another component related to this project was initially envisaged as a EUR 2.45 million infrastructure investment into six institutions, but this plan was modified after pressure by MDRI-S with the support of national and European disability and human rights organizations, who argued that such an investment would not only impede the DI process, but was also not in compliance with the obligations arising from the ratification of the Convention. Grants to local communities are planned for helping to develop and implement models of community service for the de-institutionalisation of the target beneficiaries. This is the first major investment in Serbia for developing services for adults with intellectual disabilities living in institutions.

Secondly, community care is still financed only on a small-scale and short-term basis. The Social Innovation Fund (SIF) was regarded as a major stakeholder in identifying new approaches to social protection (pilot projects) and their systematic acceptance. This fund was used to support organizations, state-run institutions and local municipalities in implementing innovative social protection

¹¹⁰ Ministry of Human and Minority Rights, State Governance and Local Self-governance, Draft Initial Report on Implementation of the Convention on the Rights of Persons with Disabilities in the Republic of Serbia (December 2011), page 66.

¹¹¹ Table taken from Draft Initial Report, page 66. This funding was mostly spent on improvement, adaptation, building and equipment.

¹¹² Ibid., page 70.

solutions on a competitive basis. However, the SIF lacked significant relevance in terms of financial capacity. Since 2003, community care projects for children and young adults with disabilities received funding totalling RSD 78.6 million.¹¹³ This amount was invested by the Norwegian, British and Serbian governments into community solutions over a period of seven years. If we compare this amount to the government's total investment in institutions in 2010 alone, we clearly see how insignificant this amount is. Although the Law on Social Welfare recognizes a variety of services, the only service that has been systematically developed to date is that of day-care centres. The government reports that in 2009 as many as 56 municipalities recognized this form of assistance in their communities.¹¹⁴ Respite care and home care service have recently also been identified as priority services in various municipalities. Still, the range of services remains very limited, leading us to ask whether such limited choice can fulfil the specific needs of different people and their families.

This opens a third concern related to the development of community care in Serbia – the variety and appropriateness of particular forms of care. Funding from the SIF, the state budget (National Investment Plan), local budgets, the EU, USAID and other foreign donors (including private donors) is used for the development of day-care centres, mostly for children with disabilities.¹¹⁵ The EU-funded project “Developing Community-based Services for Children with Disabilities and their Families” has spent EUR 3 million on for improving local services for children with developmental difficulties in municipalities across Serbia. Again, most of the services funded through the project's 11 sub-projects are services at day-care centres. Other types of services include in-home assistance and personal assistance.¹¹⁶ We are also concerned about the fact that most services for persons with intellectual disabilities are focused on day-care centres. Day-care centres are congregate service establishments, meaning that there is a high potential for the replication of institutional practices. Particular attention should be paid to ensure that the programs offered by these centres respond to users' individual needs and that they do not negatively interfere with their right to education or work.

How Potential Users See Community Services in Serbia

Services in the community

When community services are mentioned, parents of children with intellectual disabilities and persons with intellectual disabilities initially think of specialized services created specifically for persons with disabilities.¹¹⁷ Most frequently, these are day-care centres, or speech, physical or other types of therapists. When further probed on what kind of assistance they believe would be of most help in their everyday lives, parents readily mention assistance, which could be associated with personal assistance. This assistance might involve someone getting groceries or spending a few hours with the child when they are ill or otherwise unable to do so, or someone to “take me places if I am unable.”

Parents identify “block treatment” or the lack of an individual approach as the greatest shortcoming in existing specialist services. According to them, most services are designed for a large number of persons and are not individualized. Such treatment prevents individual progress and satisfaction. Regardless of the type of service, it is crucial that each person receives adequate attention and has his own particular needs addressed. One example was given by the mother of a young woman with autism. Her daughter “has nothing concrete to be engaged in – no work commitment”, so she attends an adult day-care centre, as this is the only available opportunity for organized activity. The centre serves around 50 young people with autism.

“The environment and staff are nice, [but] there is no organization of work [...] they [the users] are not allowed to use forks when eating so they won't hurt themselves [...], they are forbidden from cooking and preparing food so they won't eat anything dirty. The woman who works there

¹¹³ Information received from the Social Innovation Fund (SIF) requested under Law on Access to Information of Public Interest (2010).

¹¹⁴ Draft Initial Report on Implementation of the Convention on the Rights of Persons with Disabilities in the Republic of Serbia, page 70.

¹¹⁵ Ibid.

¹¹⁶ Ibid., 71.

¹¹⁷ For more information on data collection please refer to Annex I.

cannot devote any time to my daughter if she has six other persons to look after. She [my daughter] is ready to become independent, but this level is not being attained.”

This situation is reminiscent of another observation by parents – a lack of trust among professional. Some made this observation explicitly, while for others it became evident once they learned how the staff organized their clients’ lives. According to most respondents, their children progressed in terms of skills acquisition and socialization because they themselves were fully dedicated to their children and worked extensively with them. For many, this meant quitting their jobs.

Most parents also identified another issue related to the professionals’ inadequate skills and attitudes: problems with early diagnosis. In the parents’ experiences, professionals engaged in diagnosing intellectual disabilities and autism do not possess sufficient, up-to-date knowledge on specific disabilities and conditions, including their symptoms. Although parents reported problems all types of disabilities, this problem was most emphasized by parents of children with autism spectrum disorders.

Parents of adult children (young and old) with intellectual disabilities also recognize that their children’s need for socialization is quite strong and remains unfulfilled. There is a huge gap in opportunities for playing sports and recreation, participating in the community’s social scene, and consequently meeting new people and making friends, particularly non-disabled ones. Naturally, this void in social life makes young people feel increasingly lonely, frustrated or tense. Going out and socializing is an important factor in the inclusion of persons with intellectual disabilities, particularly in a culture that places a strong emphasis on this sphere of life. It implicates belonging to the peer group and to the community. A mother of a young man with Down syndrome says:

“For example, I cannot go with him to a club. That would be ridiculous and he certainly wouldn’t be happy with his mother accompanying him there. But I don’t know who he can go with, and he has the same needs for fun and relaxation as all other young people.”

When probed, parents start to think of services for the general population as something their children might use as well. This may be because general services have been exclusionary to such an extent that the excluded population ceases to consider themselves regular users. As one parent sums it up, however, community services means:

“[...] that everything that exists for others, exists for them also. To use the services that already exist.”

In this light, it is worth noting that one very important problem identified by parents is the non-inclusiveness of general services for children and adults with intellectual disabilities. In most cases, the personal examples they presented constitute direct discrimination by public bodies on the basis of disability. Frequent refusals to provide services to persons with intellectual disabilities and the imposition of undue obstacles to realizing one’s rights may be indicators of systematic discrimination towards this population. Health professionals and dentists in particular were unwilling to treat children as soon as they realize that the child has a particular disability. For example, it is astonishing that all respondents stated they had either once or repeatedly experienced problems with dental services for their children. Only one parent was fully satisfied with the general practitioner health services her child received – thanks in part to the doctor’s personal and professional qualities, but also thanks to her own engagement in explaining the child’s situation. This sparked debate on whether parents’ approach might be a factor in the quality of medical services their child receives.

“A parent cannot constantly apologize for having a child who is not the same as other children. It’s a terrible stress that every time you do something you have to think whether someone will be polite or have understanding. It should be taken for granted that a doctor will be polite and that your child can get a haircut in a hair salon.”

Independent living

There is a great amount of misconception regarding the definition of independent living. When asked about the possibility of their (adult) child living independently, most parents said that this would not be possible because they lack necessary skills. But then they were able to identify their children’s

strengths and weaknesses, and after some discussion, all agreed that independent living would be possible if their child had the proper support from a trusted person. It is important for parents and families of persons with intellectual disabilities to be aware that independent living involves daily support services tailored to the person's individual needs. In other words, individual living goes hand-in-hand with personal assistance. For some parents, this discussion led them to reflect more closely on their own roles and concerns.

For instance, one mother said:

"Our children should already feel like grown-ups. We parents sometimes don't give them the room for that to happen. If they were in a position to decide, they would certainly manage. Sometimes, my daughter needs to stay at home alone, and then she does things that she wouldn't do if I were there. She needs to do things without my supervision. But I am afraid to leave her alone for a longer period of time because of certain dangers, like the stove for example."

It was clear that all parents felt a fear of the future and what might happen to their children once they are no longer able to care for them. This was expressed equally by parents of children and by parents of adults, although as might be expected parents of adults had more ideas regarding possible living arrangements. Although only two parents were able to expressly name what they wished for their children (supported living), all the other respondents who had some idea of the ideal living arrangement for their child described a situation that corresponded precisely to supported living. The parents feel that their children must have their place in the society. Some parents think their child might be able to live with a sibling, others envision them as being independent, with separate lives and jobs. All parents stated that their child might be roommates with peers, but they find it important that the children choose their roommates themselves and also find it a good idea not to restrict roommates to just other disabled persons.

From the discussion on what the future may hold, it was clear that no parents wanted to see their children in a residential institution. In fact, they considered it very important for their children not to move from their home environment. One mother said:

"I would like to know if there is some sort of temporary living assistance. For instance, if you [the parent] need to go somewhere like a hospital or similar, someone could come for 5 or 10 days and stay in the home of the person who needs assistance without that person having to be transferred anywhere? This kind of support would be really needed."

All groups of parents underlined the existing lack of reliable information, which adds to the difficulties faced by families.

"Parents are very poorly informed and do not know their rights. They very much have to rely on each other. None of us [a group of parents with primary-school-aged children with intellectual disabilities] receives a government care allowance because we don't know what the consequences might be. [...] In order to receive such financial assistance, a child with autism must be labelled 100% invalid. I am worried about how this might affect my child's future. What if, once he is 18, he gets an opportunity for a job but cannot be hired because he is 100% invalid? [...] I asked the people at the centre for social work and they don't know. What does it mean to be divested of legal capacity? What does it mean to extend parental rights? There is no one to ask."

Parents frequently receive incomplete or misleading information from public servants. They feel as if they need to be lawyers in order to be able to claim some of their children's basic rights. This is especially true today, when reforms are being implemented that are met by fierce resistance on the part of the system. In such times, families of persons with disabilities need even more legal predictability and security. Timely, accurate, complete and accessible information is a key. It is vital that those who need information receive it even without direct inquiry, and that they are informed of all the implications and consequences of their decisions.

What does the realization of the Article 19 of the CRPD mean for persons with intellectual difficulties living in institutions? A personal story.

E and M spent most of their lives in Srem?ica, an institution for children and adults with intellectual disabilities near Belgrade. When they were in their forties, they received an opportunity to begin a new life in a completely different setting – an apartment in the city. Now they live in two separate apartments in Belgrade, each with their chosen roommate. They both remember exactly how and when they left the institution about five years ago to go into supported living units in Belgrade.

M does not remember how old he was when he came to Srem?ica, but he remembers the exact details of how his mother was told by experts that he could not attend school like any other children. Before coming to Belgrade, he says he used to live in a group of 17 persons. Each bedroom had 4 beds. “We could leave the institution only when we announced in advance and we had to come back on time. I went where I wanted, but it’s not the same. I had a girlfriend at Srem?ica, but then she left [to go into supported living]. We continued seeing each other, but it wasn’t the same. Now, my girlfriend and I live just like all other people.” In his free time, when not working, he goes to the gym, plays football, goes to concerts and attends a fishing course. He is also the member of a mobile assistance team that is engaged in daily activities and socialization with disabled persons who live with their families in Belgrade, but who are isolated due to a lack of support. M assists two boys and takes them around the city. M also says: “There [in Srem?ica], I didn’t know how to cook. Here I learned slowly, they [the support team] showed me how to make Chinese meatballs, beans, and paprikas.”

E says that she and her roommate, who was her friend back at Srem?ica, need most help with medical assistance, medication and cooking. Most of the shopping they can do on their own, but a larger supply of shopping is done with the help of coordinators. She says that most of their problems with independent living at the beginning were related to cooking and food preparation. “It was difficult to do anything then, because I knew only how to make coffee”. E also helps another disabled girl go out into the community more often and socialize. She likes an active lifestyle, so she works six days a week. On her one free day, she goes to self-advocacy meetings. “We learn about our rights and how to make them happen. I really like it, I am learning a lot about this because we didn’t know any of it before. We didn’t know anything.”

M works at a big furniture store, while E works in a bakery. They both seem content with their working environments and with the support they receive. Still, their support coordinator emphasizes that as long they receive an allowance, they cannot be employed legally due to the restrictions that which Serbian law places on persons without legal capacity. They are employed in the form of “work engagement” even though they perform full-time productive jobs.

About the supported-living project

The supported-living program has been initiated and operated by the Serbian Association for the Promotion of Inclusion (SAPI), with the support of mostly international donors. The program’s users have all been de-institutionalised from the Srem?ica institution. They range from 23 to 64 years of age, with varying types and levels of disabilities. So far, the program has seven apartments with 23 users. The apartments where the users live are chosen in different parts of the city to avoid congregating them in one location and to encourage them to make varied social contacts. Each apartment has a support team and a coordinator. Some of the support, as was the case with E and M, is intensive only in the beginning and becomes more occasional later on. After two years of training, users are taught how to use mobile phones so that they can call their coordinators when they need to – they control how frequent the support will be. In other cases, however, the support is more intensive – four users receive 24-hour support. The users themselves choose their roommates. All the activities and hobbies are chosen according to the person’s interests.

Conclusion

Based on the information provided, we may conclude that institutional care continues to receive a significant amount of funding, a large part of which is directed to infrastructure improvements and diversification of services. Adding new services to the institutional system is inherently problematic because the system has never undergone a change in attitudes towards and treatment of persons with intellectual disabilities.

In light of the development of community services, foreign donors and the Serbian government have recognized the need for improving the status of disabled persons, particularly children with intellectual disabilities. All such projects are valuable and necessary. However, certain initiatives are not in full compliance with international human rights standards. In particular, those initiatives and policy documents based on the notion that some children will have to stay in institutional care need to be reconsidered. A policy that legitimises unequal treatment on the basis of a person's disability is susceptible to international scrutiny. The notion that the state decides which children must remain in institutional care does not have a basis in the CRPD, nor can it be rationally justified with the concept of inclusive societies and the establishment of services designed for persons with all types of disabilities.

Similarly, it is necessary to scrutinize community services that are based on the notion that some children with disabilities cannot be included in education. There is no legal basis for excluding children from schools; all children must be included in the education system regardless of age and disability. Community services should serve to support this.

Recommendations:

- Develop a more decisive policy in the field of de-institutionalisation, with forecasting of specific deadlines, steps and funding as envisaged for the transformation and eventual closure of residential units. Policy must be in conformity with the CRPD standards, which clearly confirm the right of each person to living in the community;
- Designate a specialized unit (preferably within the existent ones) for coordinating all projects of various funding origins that are involved in developing and improving community services,
 - > The specialized unit should also be responsible for transferring best practices from countries with a well developed network of community services;
- Ensure that all parents, particularly those in smaller towns and rural areas, are familiar with community services, and that they have access to additional information on how they can influence establishing of these services in their communities;
- Strengthen and spread supported-living services through use of beneficiaries' own housing units and by establishing support services;
- Work to transform day-care centres into resource centres for supporting parents and families, with the aim of including children in the education system or finding opportunities for adult employment;
- Work on professionalism / build skills among all service providers, particularly those in mainstream services, and ensure that professionals follow current reforms and changes in attitudes;
- Make all community services individually tailored, responsive and accessible to people with disabilities.

EDUCATION

Legal and Policy Analysis

Article 72 of the Serbian Constitution states that everyone has a right to education, that basic (primary-level) education is free and compulsory, and that high-school (secondary) education is free (though not compulsory). The right of children with developmental difficulties (including intellectual disabilities) to free education is implicitly contained in this part of the Constitution.

The Law on the Basics of the Education System¹¹⁸ further regulates the education of all children, including those with developmental difficulties. It defines general educational principles such as the quality of and access to education, a focus on the child, equal opportunities and freedom from discrimination, as well as general educational goals and standards. The law also contains a non-discrimination clause, which is introduced as the primary general principle of the education system. It states that the system must ensure that all children, students and adults have equal rights to access to education without discrimination on the basis of gender, social, cultural, ethnic, religious or other affiliation, place of temporary or permanent residence, material or health condition, difficulties in development and disabilities, or on any other basis.¹¹⁹ The law further emphasizes that children, students and adults with developmental difficulties and disabilities should have access to all levels of education, and that persons in institutional care and sick children and students have a right to education during their time at the institution or hospital or while in home treatment.¹²⁰

School Enrolment of Children with Developmental Difficulties

Article 98 of the Law on the Basics of the Education System regulates the enrolment of children in schools. These provisions of the law are of significant importance. Schools have a duty to enrol all children within their district in the first grade. Schools may enrol children another school district at the request of the parents and in accordance with the school's capacity. The role of local government is to keep a register of the local population and to inform schools and parents or guardians about children who have reached the age for mandatory enrolment. All children between 6.5 and 7.5 years of age at the start of the school year must be enrolled in school. Children are tested for their readiness for school only if they are younger than 6.5. In all other cases, testing is done only after a child is already enrolled.

Testing is conducted in a standardized manner in the child's native language. The tests are adjusted for children with motor or sensory disabilities in order to provide the optimum conditions for taking the test. The tests may be used only to recommend a further assessment of the child's need for additional support or, if the child is younger than 6.5 years, to recommend postponing enrolment for another year. As opposed to the situation prior to the passage of this law, testing may not be used to defer (or even recommend) the child to a special school.

During the initial testing, schools may also establish the need for an individual educational plan or for additional educational support. Should this support require additional financial resources, the school sends a request to its funding agency¹²¹ on the basis of the opinion of an intersectoral commission for the assessment of a child's need for additional educational, health or social support.¹²² According to the rulebook, the members of the commission are as follows: permanent members are representatives from the three systems (health, education and social care), while the number and profile of

¹¹⁸ Official Gazette of the Republic of Serbia, No. 72/2009 and 52/2011, Law on the Basics of the Education System.

¹¹⁹ Ibid., Article 3 (1).

¹²⁰ Ibid., Article 3 (4).

¹²¹ Unfortunately, the funding agency is not required to provide these resources.

¹²² Law on the Basics of the Education System, Article 98, paragraph 6.

temporary members may vary for each individual child. Temporary members may come from the system as well, but they must be familiar with the particular child.¹²³

The new law changes the commission's role in assessment. Unlike before, when it decided on whether the child should attend a regular or special school or whether the child should attend school at all, the commission can no longer make any binding decisions regarding school placement.¹²⁴ Today, the commission issues an opinion regarding the support each individual child needs in order to receive an education. The commission may also issue an opinion stating that it is in the child's best interests to be educated in a special school – in such a case, the opinion must contain specific reasoning as to why the child cannot receive the support it needs in regular school. Children cannot be enrolled in special schools without the express approval of a parent/guardian.¹²⁵

The law introduces excellent affirmative action measures for children from vulnerable social groups. This means that the law recognizes that certain individuals in Serbian society do not enjoy equal opportunities and equal access to preschools and schools, and provides for easier and simpler means of access to education. For example, children may be enrolled in school even if they did not complete a preschool program, since for various reasons most children with developmental difficulties or Romany children do not attend preschool. Children from vulnerable social groups can also be enrolled in school without proof of residence or identification documents, which is of importance for Romany children since many of them are still legally "invisible".

By adopting the internationally accepted terminology for disabilities, the new law finally ends the use of outdated and stigmatising classifications. Moreover, the strict and exhaustive provision on children's school enrolment ensures that the categorizing will no longer be practiced. Today, all children have a place in the education system, and what is most important, in a mainstream school. The decision as to the type of school that a child will attend rests solely with the child's parents or guardians. The commission may only make well-justified recommendations.

Measures for Support

The central feature of the law for promoting inclusion is a detailed prescription of support measures for use by schools. The wide range of measures can be used to help children overcome barriers, and include changes in teaching and/or testing ranging from minor to more extensive. A special rulebook provides the framework for measures that can be employed by schools in order to provide children with appropriate support by removing physical and communication barriers (individualized model of work).¹²⁶ These measures include:

- Changes in the school's physical space and teaching conditions:
 - > Removal of physical barriers,
 - > Creation of additional or special forms of activities,
 - > Creation of a special timetable of activities,
- Changes in teaching methods,
- Changes in teaching materials and tools,
- Changes in the assignments or testing (phrasing), or in how learning is organized,
- Changes in the speed and pace of learning and progress,
- Specific ground rules for behaviour and communication.

These measures are defined only in a general manner and provide a framework for the creative methods that school staff can apply in order to provide some form of support for children with intellectual or learning disabilities. These measures are designed for children based on a pedagogical profile that has been developed by a school professional and the child's teacher after noticing that a child requires additional support in learning, social development, or communication.

¹²³ Official gazette of the Republic of Serbia, No. 63/2010, Rulebook on Additional Education, Health and Social Support to Child and Student, Article 6.

¹²⁴ Generally, children who were assessed with moderate or severe mental incapacity (according to an old categorization), were labelled 'uneducable', while children who were deemed to be with mild mental incapacity were referred to special schools. This practice was actually outside of the scope of authority of the commission – and was clearly violating the earlier-mentioned constitutional provision on compulsory primary education.

¹²⁵ Law on the Basics of the Education System, Article 98 (7).

¹²⁶ Official Gazette of the Republic of Serbia, No. 74/2011, Rulebook on closer instructions for establishing a right to individual educational plan, its implementation and evaluation, Article 4.

If a child does not attain the envisaged educational goals after the above measures are implemented, additional support is defined in individual educational plans (IEP) for that child. The IEP is developed specifically for a particular child by professionals and experts who know the child closely. The goal of the IEP is to achieve the student's optimal inclusion within a regular educational setting and his or her emancipation within the peer group.¹²⁷ The IEP can take many shapes and forms. The two primary types of IEP are adjusted IEPs (which do not alter the curriculum, but only the teaching and/or evaluation methods) and modified IEPs (in which the curriculum is changed).¹²⁸ Acknowledging that any change in curriculum is a serious matter, the modified IEP contains two safeguards: it may be introduced only after the adjusted IEP has been applied and after it has been verified by the intersectoral commission.¹²⁹ IEPs can be administered for one subject, for a group of subjects, or for all the subjects that the child is taking. The rulebook further regulates the IEP's contents: personal data and a short description of the child and his or her educational situation, the goals of educational work with the child (the specific changes required, including provisions for additional support and a description of support measures) in group and individual work activities, the standards that are being adjusted, the persons involved in providing support, and the time period and frequency for each support measure.¹³⁰ The child's grading is done in accordance with the child's IEP.¹³¹

One important form of support provided by the law is the teaching assistant.¹³² He or she provides additional support in accordance with the student's needs, and also assists teachers, educators and professional staff with the goal of improving their work with children and students in need of support. It should be emphasized that the teaching assistant is not necessary for all children with developmental difficulties – due to the wide range of individual support measures available to children, most of them will not require an assistant. Also, since the law defines the role of the assistant as a supportive member of the teaching staff, the assistant may be engaged in working with more than one child and may certainly be engaged in working with all the children in the class, not just those with developmental difficulties. Additionally, the role of the teaching assistant should not be confused with the role of a personal assistant. Personal assistants attend to one child and his or her needs such as movement, clothing, hygiene, eating, and similar, which are not directly related to education.

Other Important Legal Aspects of Inclusive Education

Parental participation is crucial for each step of this process, including the creation and implementation of individualized measures. This is a complete shift from the previous approach, when in most cases experts and commissions decided on the child's education and future without consulting the parents. Today, parents must be informed in writing about any specific measures (or plans for such) affecting their child, must be included in the planning process, and must provide written consent for the plan's implementation. Parents may also take an active role by including a trusted expert in planning their children's support measures and educational objectives.¹³³ These provisions are intended to safeguard children from arbitrary actions on the part of schools, and to ensure valuable input on the child's individuality, including specific abilities, preferences and characteristics.

Significant systemic changes are also contained in the regulation on the status of special schools in Serbia. Although the special education system continues to exist – Article 27 defines the types of schools in the Serbian educational system by specifying that schools for the education of children and students with developmental disabilities can still exist at both the primary and secondary levels – the regulation contains an important provision, according to which schools for children with disabilities may provide additional educational support for individuals with developmental disabilities in preschool groups, at other schools, and within the family.¹³⁴ Within this inclusive system, the special

¹²⁷ Law on the Basics of the Education System, Article 77.

¹²⁸ Rulebook on closer instructions for establishing a right to individual educational plan, its implementation and evaluation, Article 7.

¹²⁹ *Ibid.*, Article 7.

¹³⁰ *Ibid.*, Article 5.

¹³¹ *Ibid.*, Article 9 (5) and Official Gazette the Republic of Serbia, Nr. 74/11, Rulebook on Grading Students in Primary Education, Article 7.

¹³² Law on the Basics of the Education System, Article 117.

¹³³ Law on the Basics of the Education System, Article 77 (7), and Rulebook on closer instructions for establishing a right to individual educational plan, its implementation and evaluation, Article 8 (4).

¹³⁴ Law on the Basics of the Education System, Article 27 (3).

educator clearly plays a supporting role for the regular system. Nevertheless, this clause should not be interpreted to mean that the special school system plays a resource role, since the system lacks any prior experience in including children with developmental difficulties in regular schools. Another important provision of the law states that education must not endanger or violate the child's other rights.¹³⁵ Children with developmental difficulties often have to leave their homes in order to be educated in special schools, since in Serbia many such schools operate as boarding schools. The special schooling system should thus be alerted to the fact that education should not interfere with a child's right to family life and living in the community.

Most of our analysis so far has been focused on primary-level education (grades 1 through 8), which is also the focus of the law. However, the law is quite consistent in emphasizing the right to education and freedom from discrimination for both children and adults. It applies equally to secondary education, meaning that high schools (secondary schools) have similar obligations for providing their students with support.

On the other hand, the law introduces an obligatory preparatory preschool program and defines the obligations of parents to enrol their children, as well as the obligation of preschools to accept all children. The process of preschool enrolment for the obligatory preparatory program is similar to school enrolment, with the exception that all government-run preschools (regardless of the level of government – local, regional or national) must accept all children enrolled by their parents or guardians, regardless of place of residence and (in conjunction with the non-discrimination clause) regardless of any disability or other difficulty. In fact, the law on preschool education explicitly states that children from marginalized families should be given an advantage in preschool enrolment.¹³⁶

The national policy on education still needs to be fully articulated. A new strategy is currently being drafted, and the future direction of inclusive education is not yet clear. Nevertheless, we may hope that the current laws and regulations in favour of children's rights will be further strengthened by the long-term policy plans. Additionally, the Law on Primary Schools and the Law on Secondary Schools are currently still being drafted.

Analysis of Practice

According to the government's First National Report on Social Inclusion and Poverty Reduction, the general conditions in Serbia's educational system are poor and Serbia lags far behind the EU countries when it comes to educational goals and indicators. Important problems include the low quality of education, a failure to acquire functional knowledge, a large percentage of adults with only primary-level education, and a low percentage of adults who are included in any form of education or training.¹³⁷ The quality of education is still not at a satisfactory level – curricula are still focused on content, and not on developing the skills necessary for life within contemporary society.¹³⁸ Within such an educational environment, it is difficult to expect positive experiences in the education of children with intellectual disabilities.

According to official statistics, the number of children enrolled in regular primary schools in Serbia is growing. According to the data for the 2010/11 academic year, 1,570 (5.4%) children with developmental difficulties were enrolled in the first grade at 38% of all primary schools have. Of that number, 1,312 (4.6%) have intellectual and communication difficulties, while 258 are children with physical disabilities. The number of children with difficulties has increased from the previous year to 6.6%.¹³⁹ On the systemic level, however, the situation has not improved in terms of keeping records of children from marginalized groups, including children with developmental difficulties, so there is no reliable data for improving education policy.¹⁴⁰

¹³⁵ Ibid., Article 3 (5).

¹³⁶ Official Gazette of the Republic of Serbia, Law on Preschool Education, No. 18/2010, Article 13.

¹³⁷ First National Report on Social Inclusion and Poverty Reduction in the Republic of Serbia 2008-2010, Government of the Republic of Serbia (March 2011), page 123, paragraph 5.3.11. <http://www.inkluzija.gov.rs/wp-content/uploads/2010/03/First-National-Report-on-Social-Inclusion-and-Poverty-Reduction.pdf>

¹³⁸ Ibid., 140, paragraph 5.3.82.

¹³⁹ Statistics from First National Report on Social Inclusion and Poverty Reduction, page 125, paragraph 5.3.19.

¹⁴⁰ Ibid., 140, paragraph 5.3.81.

For the most part, children with intellectual disabilities are educated in the special education system. Besides special schools, this system includes special classes attached to regular schools, special preschool groups within regular preschools, and preschool groups at special schools. Special schooling is organized according to the type of disability, meaning that children with the same kind of disability are taught separately in special schools or in separate classrooms.¹⁴¹

The Delivery of Improved Local Services (DILS) project¹⁴² played an important role in the implementation of inclusive practice, which is being jointly realized by the Ministry of Health, the Ministry of Labour and Social Policy and the Ministry of Education. The latter is responsible for four components of this project aimed at increasing the inclusion of children from marginalized groups within the education system. As regards children with intellectual disabilities, the most significant component is “Strengthening Schools for Inclusive Education”. National training sessions were held on the implementation of the new law for five representatives from each primary school and one representative from each secondary school in the country. In addition, this particular component involved two calls for proposals for regular primary schools and secondary schools to participate in the program. A total of 281 schools were chosen, and their teachers received a free set of training sessions and could apply for small grants aimed at improving the inclusion of children from vulnerable groups. Grants were provided for different education programs for staff, for equipping the schools with assistance technologies and teaching materials, for study visits to model schools, for minor construction projects and for other activities that might contribute to quality inclusion in education. Additionally, about 20 special schools received grants and assistance in order to implement changes for enrolling children with all types of disabilities.

Studying Primary Schools’ Inclusive Education Practices

Firstly, we should note that the schools that participated in the DILS project were more responsive to our questionnaire than schools that did not participate: 32% versus a low of 9%.¹⁴³ As a result, the following picture is not representative of inclusive primary education within the country; rather, the results presented here are likely to be more positive than the average situation in Serbia. This is so because the schools that participated or are participating in the DILS project received more training and resources for implementing inclusive education. Another reason for their higher response rate might be that the support received from DILS increased the school staff’s knowledgeability, and encouraged them to be actively involved in working with children with intellectual disabilities.

Schools participating in the research

Type of school/ Response rate	Sent	Received	Response Rate
Regular schools participating in DILS projects	278	89	32%
Regular schools not participating in DILS projects	266	24	9%
Special schools	37	10	27%

Instead of offering a set criteria or a definition of intellectual disability,¹⁴⁴ we asked the schools to identify the children they regarded as having such difficulties and to explain what the basis for this identification was. Regular schools stated that 2.9% of their students had intellectual disabilities. At some schools (eight), this number was significantly higher than the average – more than 10% of the school’s total student population – and at one school, the number of students identified as having intellectual disabilities was 17%. The average we encountered is slightly higher than the worldwide

¹⁴² For further information, visit <http://www.dils.gov.rs/>.

¹⁴³ For more information on methodology, please see Annex I.

¹⁴⁴ The questionnaire also included was a set of questions for children with autism spectrum disorders. The approach was to separate the target group children because of concerns that children with autism are rarely recognized by the system and thus rarely receive the support they need. The overview of results includes children with autism in the final data; whenever the text refers to children with intellectual disabilities, this includes children with autism as well.

statistics on intellectual disabilities. However, since it is likely that not all children with intellectual disabilities attend school, especially not regular ones, we may assume that in this particular group of children with intellectual disabilities, the schools included some children with other difficulties that are not identified or diagnosed, but that the teachers identify as cognitive difficulties. These intellectual difficulties were identified mostly on the basis of a teacher assessment. In less than 50% of cases was this conclusion based on a diagnosis or medical documentation.

Students with intellectual disabilities in the education system

Type of school/ Frequency	Students with intellectual disabilities	Total number of students	% of children with intellectual disabilities
Regular schools	1,704	59,298	2.9%
Special schools	825	858	96.1%

All schools that participated in this study had at least one child with an intellectual disability. Also, children with intellectual disabilities can be found at all grade levels (1 through 8), which means that inclusion was being practiced prior to the explicit legal obligation to do so. This may be in part because some of the children's difficulties were not recognized prior to the enrolment, but also in part because some schools exercised goodwill in enrolling children with known intellectual disabilities. There is anecdotal evidence that, prior to the new law, some parents felt pressured to hide their children's disability because they feared that their children would not be able to realize their right to education otherwise. The number of children with intellectual disabilities is slightly but noticeably higher in the first grade at regular schools. Of all the children identified as having intellectual disabilities at regular schools, 18.0% were in the first grade and 15.1% in the second grade. In all of the higher grades, the percentage is between 6.9% and 13.4%.

Support measures

Since the law requires that first step in planning support is to create a pedagogical profile, it is troubling that almost half of students (43.6%) at regular schools with intellectual disabilities do not have a pedagogical profile. Only 38.1% of regular schools have created a profile for all the students they have identified as having an intellectual disability. The situation at special schools is similar, but perhaps more surprising considering the fact that special schools have had experience with students with intellectual disabilities and are considered resource centres for teaching this group of students. Forty percent of special schools have created profiles for all of their students with intellectual disabilities, while 20% have not even started this process. In general, a little more than half (56.8%) of all children with intellectual disabilities at special schools have a pedagogical profile.¹⁴⁵

Pedagogical profiles at schools

Type of school/ Frequency	Number of students with intellectual disabilities	Number of students with intellectual disabilities with pedagogical profile	% of children with intellectual disabilities with pedagogical profile
Regular schools	1,704	961	56.4%
Special schools	825	469	56.8%

¹⁴⁵ The figures for completed pedagogical profiles among students with autism are more favourable. This may indicate that schools either take autism more seriously as a disability – based on the existence of a medical diagnosis – or that they find it easier to develop profiles for this student population because there usually are fewer of them.

Schools rarely plan measures for the removal of physical and communication barriers (individualization measures): this was done for 36.3% of students at regular schools and 19.3% of students at special schools.¹⁴⁶ One reason that this is not done more often is that producing a written document is not obligatory and that it requires some sort of strategic planning for the child.

Individualization measures at schools

Type of school/ Frequency	Number of students with intellectual disabilities	Number of students with intellectual disabilities with individualization measures	% of children with intellectual disabilities with individualization measures
Regular schools	1,704	619	36.3%
Special schools	825	159	19.3%

The next step is the creation of an individual educational plan. At regular schools, only 26.6% of students with intellectual disabilities have an adjusted IEP in which the curriculum remains unchanged, while 9.2% have a modified IEP with an altered curriculum (in total, slightly more than one third of all children who need some form of support have an IEP). It is difficult to conclude whether the schools follow the law in performing the required steps, since this is not always clear from the cumulative information provided. However, we may state with certainty that at least 12 regular schools (nearly 10.6% of all schools surveyed) create an IEP prior to developing the student's pedagogical profile.¹⁴⁷ It is a positive sign that modified IEPs are used more rarely than adjusted IEPs, since changing a child's curriculum is a serious undertaking and should be done only as a last resort.

Numbers and percentages of IEPs for students with intellectual disabilities at regular schools

Frequency/ Type of IEP	Adjusted for 1 class subject	Adjusted for a group of class subjects	Adjusted for all class subjects	Modified for 1 class subject	Modified for a group of class subjects	Modified for all
number of IEPs developed	86	323	45	8	109	40
% of all students with intellectual disabilities	4.9%	18.9%	2.6%	0.5 %	6.4 %	2.3%

Numbers and percentages of IEPs for students with intellectual disabilities at special schools

Frequency/ Type of IEP	Adjusted for 1 class subject	Adjusted for a group of class subjects	Adjusted for all class subjects	Modified for 1 class subject	Modified for a group of class subjects	Modified for all
number of IEPs developed	16	28	35	7	36	78
% of all students with intellectual disabilities	1.9%	3.4%	4.4%	0.8%	4.4%	9.5%

¹⁴⁶ Again, this measure is more frequently applied to students with autism.

¹⁴⁷ There were more IEPs than pedagogical profiles (110 profiles and 149 IEPs).

The law provides a useful opportunity for schools to develop the IEP in collaboration with a professional recommended by the parents who is familiar with the child. However, schools generally do not take advantage of this possibility – almost 80% of regular schools and 70% of special schools did not include a professional from outside the school who was familiar with the child.

When we look at children being referred to intersectoral commissions whose role is to verify that education takes place at a special school (with the parent's approval) and, more importantly, to authorize specific types of support measures requiring additional financial resources (e.g., assistants, transportation, medical treatment), we noticed that regular schools refer an average 11.2% or 190 children with intellectual disabilities to the commission. Children in the first and second grade are referred at an only slightly higher rate, which corresponds with the slightly higher number of children identified as having difficulties in these two lowest grade levels. We also noticed that, out of 157 students being taught under a modified IEP (the most drastic measure envisaged), 23 were not evaluated by the commission in terms of their need for support. In other words, their need for this serious measure was not sufficiently verified.¹⁴⁸ Another troubling fact is that special schools rarely refer children to the commission – not a single student with intellectual disabilities from the higher grade levels was referred to the commission, and only 26.3% of first-graders with an intellectual disability (20 out of 76) were referred. It is puzzling how the other children (74% of all first-graders at special schools) were enrolled in a special school in the first place without a needs assessment by the commission, since the law requires the commission's verification (with the parent's approval).

Capacity-building

At 83 regular schools (73%) and 4 special schools (40%), all members of the inclusion team had attended Ministry of Education workshops on the new law's inclusion provisions, with a maximum of five persons from each school participating. For those schools that did not train all staff members, the stated reasons included: the team had more than five members, the director was changed in the meantime, and new persons were hired onto the inclusion team. Fourteen regular schools (12%) did not answer whether they had any issues or unanswered questions following the national training sessions, while eight (7%) stated that they did not have any issues or unanswered questions. The most common issues were related to grading students under the IEPs, keeping proper records and documentation, the role of the intersectoral commission, difficulties in working with parents, how to implement in practice what they had learned, the difference between adjusted and modified IEPs, and the criteria for deciding which kind of IEP to use. Most representatives from special schools stated that they were unsure as to whether their students should have IEPs. Examples of concerns voiced by the schools include:

“The biggest dilemma is how to include children with more serious developmental difficulties, which plan to use when working with them, what the educational standards are, who develops them and how to grade children who work under an IEP.” (special school)

“Even after the [national] training sessions, we are still not clear as to when and for which students we need to develop an adjustment plan [individualization measure], and when to use an adjusted versus modified IEP (in practice we have problems with identifying children)”

“The teaching staff is concerned that they are not competent enough to work with children from vulnerable groups; teachers required assistance from defectologists¹⁴⁹ and speech therapists.” (regular school)

The schools were asked whether their staff attended any other trainings or workshops in connection with inclusive education. In addition to the training sessions organized by the Ministry of Education, many civil society organizations have been organizing similar events throughout Serbia since the enactment of the new law.¹⁵⁰ According to those who stated that they had attended seminars and

¹⁴⁸ As this happened in three schools only, it might be the case that the commissions in those particular localities were not formed at the time.

¹⁴⁹ Special education teachers.

¹⁵⁰ Initiative for Inclusion VelikiMali, Association of Students with Handicap, MDRI-S, Centre for Interactive Pedagogy, Open Society Fund, Teachers' Association, etc.

trainings on the subject (94 schools, both regular and special), the most common themes encountered at these sessions were: motivation and psychological principles of learning, inclusive education and individual educational plan, inclusive education – strategies and measures for adapting the classes. Also, 75% of regular schools said that they shared experience with other schools, both formally and informally, while the same can be said for 60% of special schools. Schools use the other schools' experience to improve the knowledge of their own staff, but there is still a lot of room for improvement and for a more widespread horizontal transfer of knowledge.

This high number is somewhat in contradiction with answers indicating that schools were not very familiar with the Inclusive Education Support Network established by the Ministry of Education. The network was established at the national level and consists of staff and experts from schools and other state institutions from all over Serbia who have experience in including children in regular classes. Their contact information is available to all teachers and staff in case they encounter challenges and obstacles in working with vulnerable children. Nevertheless, many schools do not make use of this network in their work (65% of regular schools and 80% of special schools, with 6% of regular and 10% of special schools not providing an answer). Moreover, if we take a closer look at the answers provided by some schools that said they used the network, we see that they are actually referring to informal networks established among several schools on their own initiative. This shows that schools may not be aware of the network's existence and role. The importance of this network for the practical work of teachers and professionals at schools cannot be emphasized enough.

The schools were asked to descriptively grade the support they received from the Ministry of Education. The responses vary from "excellent" to "completely unsatisfactory". Around 26% of all schools evaluated the ministry's support from as being inadequate or negative, while 34% gave a satisfactory or very positive evaluation (some 28% provided answers that could be described as neutral and 12% did not answer the question). Following are some typical responses to this question:

"Inclusive education is currently receiving exactly as much attention as needed. The members of the expert team for inclusive education attended all free training sessions, and the school has the opportunity to provide additional resources and to improve its work with children from vulnerable groups by participating in projects."

"We would grade it with a 3 (average). Some teachers attended the training sessions, but most are confused and don't understand their role in implementing inclusive education."

"It is not enough. We did not receive any preparation for introducing inclusive education, so teachers were confused, and were afraid to write IEPs because they worried about making a mistake."

As regards the next steps for enhancing work with children with intellectual disabilities, 111 (90%) of the surveyed schools stated what their needs were. This is an encouraging fact in itself, since it tells us that schools are thinking in terms of improving the future and how to overcome current challenges. Most of the answers indicate that schools are thinking in terms of the practical steps they need to take, which tells us that resistance to inclusion can be overcome through support from the authorities at various levels.

- Most schools, both regular and special (65% and 50% respectively) identified their biggest need as being free training sessions and staff education;
- 34% of regular and 50% of special schools stated that they lack modern teaching materials;
- 21% of regular schools felt that they need personal assistants or teaching assistants in order to provide better services;
- nearly 20% of regular schools stated that they find the help of experts indispensable;
- nearly 10% of regular and 40% of special schools see a need for introducing assistance technologies in teaching.

Other stated needs included: specialized literature, fewer students per class, a sensory room, adapted textbooks, study visits to other schools and sharing experience with colleagues, increased stimulation and rewards for working with children with intellectual disabilities, laws and rulebooks that are clearer, more precise and more easily implemented in practice.

Survey of Parents of Children with Intellectual Disabilities

Parents in the survey

Frequency/ Type of school	Attending regular schools	Attending special schools	Total
Parents of children with intellectual disabilities	19	6	25

Most parents say that they have not encountered any difficulties in enrolling their children in school. Three parents said that they encountered problems enrolling their children in regular schools, but that was before the new law entered into force. One parent said that there were problems with the special school, which resisted enrolling her child after the law entered into force:

“Yes, we had difficulties. They were solved in that I sit with my child at the school in the role of the child’s personal assistant, with my job hanging by a thread. If that can be called a solution, then we found one.”

Approximately half the parents said the child had no problems adapting to the school environment, while the other half said that there were problems. Some of problems they encountered include:

“Yes, our child had great difficulties studying. As a result, he was not interested in working and in other school activities, but we solved this with the help of the teacher.”

“Our boy was brutally beaten and abused in the first grade by his peers, he was bruised and his situation deteriorated immensely, leading to stress, fear and a rejection of school as well as a sudden weakening of his immune system and decline in health. He was immediately transferred to a village school. To be honest, if it hadn’t been for a new teacher, he would not have recovered and regained his trust in children and people. An excellent teacher and a very stimulating environment – everyone is spontaneously included in supporting the child and I am very pleased because I see that my child is happy and likes school, friends, people and life.”

“There were [problems], of course. For the first month I sat with the child at her desk. The next month she had an assistant, and now she is alone since the municipality refused to pay for the assistant despite the fact that the school was promised the funding.”

In most cases, parents evaluate teachers’ cooperation with them and their children as good or excellent. In some cases, they state that cooperation is good with some teachers but poor with others. A few parents described their cooperation with the teacher as very poor. We noticed a lower level of cooperation in the higher grades (above the fourth grade), when children have different teachers for each subject:

“In the lower grades, our cooperation with the teacher was excellent, but in the higher grades, some teachers have been not willing to accept a different way of working as opposed to the rest of the children.”

“...most teachers ignored the child’s problem and did not help. One teacher even put up obstacles.”

“Both the teacher and the environment are remarkable, very stimulating. Everyone is spontaneously included in supporting the child, and I am very content because I see that my child is happy and enjoys school, friends, people and life.”

Experiences with other children in the class varied from across the entire spectrum, from positive to negative. In most cases, parents considered their children to be content and well accepted by their peers. There were problems in a few cases, but these were overcome. In some cases the child’s relationship with his peers varied, and in some other cases there was no contact or with other children or the contact was described as highly negative.

Some of the parents' statements include:

"At first, they didn't accept him, and he didn't even accept himself, but then I became involved as a mother and started initiating some interesting situations in an attempt at drawing in some of his classmates. He now has many friends."

"When the children were younger, everything was fine, but now they are starting to behave worse towards her. She can feel it, and is bothered by it. This is a problem that we still have not managed to resolve." (8th grade)

"They [the other children in class] still do not understand why she receives preferential treatment."

"At the first parents' meeting, which was held after 4 days, several parents stated that their children were suffering because they were in a class with my child. Now they have gotten used to it. I am so satisfied with the children's attitude towards her... They accept such children much easier than their parents".

Most parents with children in regular schools stated that their child had a pedagogical profile (14 out of 19), but it is important to note that two parents did not partake in its creation and that three parents do not even know whether a profile was created or not. Another two parents of children at special schools were not familiar with these profiles. Many parents realize that individualization measures (adapting teaching and communication methods to the child's needs) are being implemented even if no pedagogical profile has been created. However, two parents did not know this as well.

According to the parents, schools have a strong tendency to justify that it is enough to develop the child's IEP only orally (one parent stated that she did not receive any explanation). Only one parent received this information in writing, in accordance with regulations. Moreover, although the rulebook is explicit about this, only seven out of 19 parents gave their written consent to creating an IEP for their children – the schools requested only oral consent. Three parents out of the 19 whose children have an IEP did not know what kind of the plan (adjusted or modified) was developed, and whether the IEP covered just one subject of instruction or all of them.

It is usually the parents, and not the schools, who initiate a needs assessment for additional support before the intersectoral commission. Parents initiated the needs assessment in 10 cases, the schools did so in four, and the centre for social work in one case; one parent did not know if an assessment was launched or not. In some cases, the assessment procedure was in progress, in others the commission identified the child's need for a pedagogical or personal assistant. According to the parents, in nearly 40% of cases the child receives support solely from their family. In three cases, the child's teaching assistant is financed by the state/school, and in three additional cases the assistant is financed by the parents or an NGO. Two other parents financed a personal assistant for their child.

Education of Children with Developmental Difficulties Residing in Institutions

Finally, it is important to know how the right to education is being realized for children developmental difficulties living in residential care.

Children in institutions by school age, September 2011

Institutions/Frequency	Attending regular schools	Primary-school age	Secondary-school age	Total
Home for Children KOLEVKA, Subotica	72	103	1	176
Home for Adults KULINA, Aleksinac	0	Information not provided	Information not provided	126
Home for Children and Adults SREMCICA, Belgrade	6	74	14	94
Centre for Placement of Children and Youth with Autism, Belgrade	0	Information not provide	Information not provide	2
Home for Children and Adults „DR NIKOLA ŠUMENKOVIĆ“, Starnica	0	32	22	54
Home for Children and Adults VETERNIK, Novi Sad	0	70	50	120
Centre for Children ZVECAN-SKA, Belgrade	57	64	8	129
Total				701

The tables show that the largest number (566) of children with developmental difficulties living in institutions are primary- and secondary-school aged, while only three institutions are home to preschool-aged children and younger. The following table provides an overview of the extent to which these children receive education as mandated by the Constitution and by national laws. Just over two out of three (67.6%) children who should be attending primary school are not included in any form of education. Significantly, only one institution – Sremcica near Belgrade – claims to include all of its children in schools, both primary and secondary. On the negative side, three institutions have absolutely no practice of enrolling children in school, while two do so only sporadically.¹⁵¹

A clear trend at all levels of education is to include children in special education. This is highly unfortunate, because preschool and school are the most important (and only) places where institutionalised children can interact with non-disabled peers. The practice of non-selective enrolment of children with developmental difficulties in specialized education is also inconsistent with international standards, which state that children should be included in regular education and should be place in specialized classes only in exceptional cases.

¹⁵¹ This practice is a holdover from professionals' traditional attitude that children with intellectual disabilities are "uneducable" – incapable of learning, accomplishing, or being a valuable member of society. While these attitudes certainly need to change as a matter of urgency, it is clear that they cannot serve as justification for encroaching upon the right to education of children with developmental difficulties, in particular in light of today's constitutional and legal guarantees.

¹⁵² The above data should be taken with a grain of salt, since follow-up visits by the monitoring team uncovered certain disparities between the data provided and the actual situation at the institutions. (opposite page)

Education received by school-aged children¹⁵²

Institution	# of primary-school age children Attending regular schools	Attending regular school	Attending attached classes at regular school	Attending special school	% included in primary education	# of secondary-school age children	Attending regular school	Attending special school	% included in secondary education	# of preschool-age children	Attending regular preschool	Attending special preschool group	% included in preschool
Kolevka Children's Home, Subotica	103	0	0	5	5%	1	0	0	0%	72	0	7	7
Kulina Home for Adults, Aleksinac	unknown	0	0	0	0%	unknown	0	0	0%	0	NA	NA	NA
Home for Children and Adults SREMIČICA, Belgrade	74	0	0	74	100%	14	9	5	100%	6	0	0	0%
Centre for Placement of Children and Youth with Autism, Belgrade	unknown	0	0	0	0%	unknown	0	0	0%	0	NA	NA	NA
Home for Children and Adults „DR NIKOLA SUMENKOVIC“, Stamnica	32	0	0	0	0%	22	0	0	0%	0	NA	NA	NA
Home for Children and Adults VETERNIK, Novi Sad	70	0	0	29	41%	50	0	3	3%	0	NA	NA	NA
Centre for Children ZVEČANSKA, Belgrade	64	0	0	3	3%	8	0	0	0%	57	0	14	14
Total	343	0	0	111	32.4%	95	9	8	17.9%	135	0	21	15.6%

What does the realization of Article 24 of the CRPD mean for children with intellectual disabilities? A teacher's story.

Five years ago, the first boy with autism spectrum disorder was enrolled in our school. Prior to this, he had attended a preschool program in the autism classroom of a special school. This is how our school first developed a strategy for preparing our school (environment and staff) for working with children with developmental difficulties.

The following year, a boy with “multiple difficulties” related to his intellectual functioning, communication, social relations and independence was enrolled in my class. After one month, we determined that his difficulties were in fact autism spectrum disorder. This is when we wrote his first individual educational plan.

I cooperated quite a lot with my colleague who was teaching a child with similar disabilities who had enrolled one year earlier. Defectologists [special-education workers] from the Autism Centre came to help us work with these children: How to approach them, what methods to use in communicating with them, etc. The most important thing we learned was that a peer group is the biggest motivation for these children. Each subsequent academic year, we had one or two children with autism spectrum disorder. We continued our horizontal (teacher-to-teacher) learning and support, but also collectively attended numerous training sessions on working with children with developmental difficulties. We cooperated with numerous civil society organizations, and also received much support from parents. We included one teaching assistant in our work, who came daily to one classroom and worked individually with these or other children. Her main task was to explain those subject matters to the child that he could not grasp at the same pace as the other children (reading and writing, the concept of numbers, mathematics, explaining the relationship between cause and effect). All this was done during regular classes when the rest of the children were working on similar content matter.

Working with this boy is completely different than with other children. He reacts only when addressed directly, has immense difficulty focusing on his assignments, does not give feedback and does not ask for help. This requires us to adapt our work to his needs. Since he is in a class with 23 other children – peers who are in a daily contact with him and who work at their own pace – he has an opportunity to learn from them, to communicate with them, to be included in work and in play. On a day-to-day level, he progresses in every way.

In order to adapt the contents of the class curriculum, we give him assignments that are more concrete. For example, because he does not understand abstract concepts such as subject and predicate, I do not ask him to name them in a sentence. Instead, I ask him to find “who does” and “what does” in a sentence and to underline those words. In this way, he finds both subject and predicate without error. He does math with the help of tables – addition and subtraction as well as multiplication and division tables, which are glued onto cardboard and which he has at hand. He calculates simple assignments using these tables at the same speed as the other children do in their heads. In this way, he is included in all of the activities: textbook assignments, math quizzes, group work, pair work etc.

On the first day of the third grade, children interviewed each other about their summer vacations in groups of three. With the help of his peer's questioning, this boy “recounted” (in short sentences and a silent voice, with pauses between questions and answers) his visit to his grandmother in Bosnia, where he played with his brothers who live there, and where he had a great time playing with a goat and two baby goats. The story intrigued the other children, and they asked him additional questions to which he responded. The children listened attentively and patiently, and all were happy. The assignment was completed, and the goals were achieved with only a minor methodological adjustment.

Most importantly, all children go through different life situations every day. I plan thematically, the topics are from life, the demands are always differentiated, the work is interactive, and the class is designed so that children can solve problems but also support each other and cooperate and progress at their own pace, through exploration, research, role playing and similar activities. In this way, the boy has an opportunity not only to learn and grow within his peer group, but also to be accepted and to prepare for life within the community on an equal basis with others.

Sonja Paripovic,
teacher at the Sonja Marinkovic Primary School, Novi Sad

Conclusion

The importance of the current Law on the Basics of Education's insistence on the right to education for each and every child cannot be overstated. While previous laws did not contain provisions that explicitly excluded children with developmental difficulties from education, the prevailing state of affairs dictated that most of these children were "uneducable", and parents had to fight the system on an individual basis if they wanted their child to go to a regular, and in some cases even a special, school. Today, parents do not have to conceal that their children need support from the system, nor do they have to worry that their children's future will depend on the goodwill of the school's authorities and teachers. For the first time, local governments will directly receive information about the needs of local children and will be able to plan their budgets accordingly. The current law is a progressive landmark law that will – if fully and consistently implemented – ensure the inclusion of all children, including children with intellectual disabilities, in regular education and will lay the foundations for broader social inclusion.

Recommendations:

- Apply sanctions in cases of gross violation of the right to education as when preschools or schools refuse to enrol a disabled child directly or indirectly by imposing certain conditions (finding an assistant, presence of a parent, etc.);
- Ensure that all teaching and professional staff receive practical training on implementing the law and relevant rulebooks, in particular the rulebooks on IEPs and grading;
- Develop rules for realizing the right to a teaching assistant, the criteria for realizing this right, and the manner of planning, hiring and financing this service;
- Promote positive examples of inclusion by highlighting different ways of overcoming specific challenges to inclusion;
- Develop and distribute practical guidelines for parents regarding their role in their child's education;
- Ensure that all schools involve parents in the processes related to planning their disabled child's education, in particular that parent receive a copy of all documents that are developed for their child;
- Enable school teaching staff to conduct study visits to model schools and to engage in the informal exchange of experience;
- Intensively inform schools, staff and parents about the existence and role of the Inclusive Education Support Network;
- Ensure that existing special schools and attached classes meet all legal requirement for providing adequate support to children, including obtaining an opinion from the intersectoral commission;
- Ensure that both regular and special schools initiate needs assessments for additional support before the intersectoral commission;
- Ensure that the schools' founding agencies (local, provincial and national governments) are aware of the importance of funding the support necessary for teaching local children with developmental difficulties living;
- Ensure that children with developmental difficulties residing in social care institutions receive education on an equal basis with others. With this in mind, develop a medium-term strategy for enrolling children from institutions into regular education at all levels, starting with preschool;
- Raise the awareness of all stakeholders regarding the role of the personal assistant and the difference between personal assistants and teaching assistants;
- Educate all stakeholders about the types and ways of using assistance technologies;
- Continually train the intersectoral commissions on the social model of disability and their role under the new law.

WORK AND EMPLOYMENT

Legal and Policy Analysis

The Constitution of the Republic of Serbia defines work-related rights in its Article 60, which guarantees the right to work in accordance with the law, (1) the right of all persons to a free choice of work, (2) that all workplaces are accessible to everyone under equal conditions, (3) the right to have one's dignity respected at work, (4) safe and healthy work conditions, all the required work safety measures, limited working hours, daily and weekly rest, paid annual time off, just compensation for work and legal protection when terminating employment. These rights cannot be waived (relinquished). Further, women, youth and "invalids" are afforded special protection at work and special working conditions in accordance with the law (5). Also relevant is Article 26, which prohibits forced labour, including the sexual or economic exploitation of disadvantaged persons.

The employment and work of persons with intellectual disabilities is further regulated by the general laws defining the rights, obligations and responsibilities related to employment of the general population, as well as a *lex specialis* that specifically regulates the work and employment of persons with disabilities.

Who Can Work?

The Labour Law¹⁵³ defines who can and cannot enter into an employment contract. To be employed, a person must be at least 15 years of age and meet other conditions for working certain jobs, as established by the law or the rulebook for the organization and systematisation of jobs. Here we encounter the first barrier to employing one group of persons with disabilities. Persons with intellectual disabilities are frequently divested of their legal capacity and placed under guardianship. The law thus views them in the same manner as persons under 14 years of age. Loss of legal capacity thus also implies the loss of the right to work. The Law on Obligation Relations confirms that in order to conclude a legally valid contract, the contracting parties must have legal capacity.¹⁵⁴ Persons with partial legal capacity, which is possible under the Family Law, may conclude only those contracts for which they have legal permission. For all other contracts, they must have their guardian's approval. This provision indicates that persons with partial capacity should be able to enter into employment contracts unless the court has explicitly stated that they cannot do so.

The Law on Professional Rehabilitation and Employment of Persons with Disabilities¹⁵⁵ represents an attempt at responding to the high rate of unemployment and non-employability of persons with disabilities. It attempts to do so through two main measures: by introducing a quota system for employers to hire persons with disabilities and through measures for active employment. According to Article 4 of the law, only those persons whose disabled status has been established by relevant state commissions or bodies may take advantage of the rights prescribed by the law. Persons without this status may benefit from the rights prescribed by the law if they undergo a work capacity assessment.

Work Capacity Assessment

The work capacity assessment is closely regulated by the Rules Detailing the Manner and Costs of and Criteria for Work Capacity Assessment and Possibilities for Hiring or Preserving the Employment of Disabled Persons.¹⁵⁶ The aim of the assessment procedure is to deliver an opinion on a person's

¹⁵³ Official Gazette of the Republic of Serbia, No. 24/05, 61/05 and 54/2009, Labour Law.

¹⁵⁴ Official Gazette of the Socialist Federal Republic of Yugoslavia, No. 29/78, 39/85, 45/89 and 57/89; Official Gazette of Socialist Republic of Yugoslavia, No. 31/93 and Official Gazette of Serbia and Montenegro, No. 1/2003 Law on Obligation Relations, Article 56.

¹⁵⁵ Official Gazette of the Republic of Serbia, No. 36/09, Law on Professional Rehabilitation and Employment of Persons with Disabilities.

¹⁵⁶ Official Gazette of the Republic of Serbia, No.36/10, Rulebook on more detailed way, costs and criteria for work capacity assessment and possibilities of employment or preserving employment of persons with disabilities.

general capacity to work, on whose basis the National Employment Service (NES) prescribes the conditions under which a person can be employed. We must note at the outset that the practice grading a person's general ability to work according to the level of "illness and damage" is not in line with the social model of disability.

Specifically, the work capacity assessment as defined by the rulebook contains grades that are fairly ambiguous and quite contentious. For example, the lowest possible grade is defined as a working effectiveness of less than two thirds of the typical employee. What is the meaning of typical employee and how can we quantify an employee's general effectiveness? Meanwhile, working effectiveness is an important criterion, since anyone who receives the lowest grade (3) cannot be employed on the open market.¹⁵⁷ Similarly, persons who are awarded the second lowest grade (2) can be employed only under special conditions.¹⁵⁸ What is more, although the work capacity assessment questionnaire contains social criteria, it sticks to the medical model. This is evident from the fact that the commission is headed by a medical doctor, and that the questionnaire contains numerous questions regarding the type of disability, while questions on the person's preferences and wishes for a particular type of work are completely lacking.

There is a clear lack of consistency in the employment of persons with disabilities. On the one hand, the law establishes a legal foundation for filing discrimination claims if the employer fails to provide reasonable workplace accommodations.¹⁵⁹ On the other hand, work capacity assessment is realized in a vacuum, independent of the specific job's assignments, tasks and specific support necessary for performing this job. In fact, a real picture on a person's capability to perform a particular job task can be received only when he or she receives adequate legally entitled support. This approach should be adopted in the work capacity assessment. Under the social model of disability and affirmative action measures for hiring disabled persons, the task of this assessment should be to assess the support required in order to perform a particular job, instead of placing advance restrictions on the forms of employment a person can engage in.

Another important point should be addressed. Since one of the conditions for registering with the National Employment Service is to be over 15 years of age¹⁶⁰ (the same as for entering an employment contract), it is clear that persons deprived of legal capacity cannot even register as unemployed job seekers. It follows that they cannot engage in the work capacity assessment procedure. It should be noticed, however, that there are no other legal obstacles for persons without legal capacity to be registered with the National Employment Service, except for the provision in the Family Law equating these persons with younger minors.¹⁶¹

Affirmative Action

Those persons with disabilities who receive a positive grade (grade 1 or 2) on the assessment may benefit from affirmative action. The law prescribes a quota system according to which all employers with more than 20 employees must hire a certain number of persons with disabilities.¹⁶² The obligation binds public as well as private enterprises. Employers can nevertheless choose to participate in alternative affirmative action measures. For instance, instead of hiring a disabled individual, they may

¹⁵⁷ Law on Professional Rehabilitation and Employment of Persons with Disabilities, Article 23, and Rules Detailing the Manner and Costs of and Criteria for Work Capacity Assessment and Possibilities for Hiring or Preserving the Employment of Disabled Persons, Article 16.

¹⁵⁸ Employment under general conditions is employment without any adaptations to the job and/or workplace. Employment under special conditions is employment with adaptations to the job and/or workplace, Article 23: adaptations to the job refers to changes in the working process and job-related tasks; adaptation of workplace refers to technical and technological equipping of the workplace, working tools, space and equipment – in accordance with the disabled person's needs and abilities.

¹⁵⁹ Under the Law against Discrimination of Persons with Disabilities; more on this later in the text.

¹⁶⁰ Official Gazette of the Republic of Serbia, No. 36/2009 and 88/2010, Law on Employment and Insurance in the Case of Unemployment, Article 2.

¹⁶¹ See for example Official Gazette of the Republic of Serbia, No. 15/2010; Articles 4 and 5 of the Rulebook on More Detailed Content of Data and Employment Record-Keeping list the kind of information necessary for a person to be registered with the NES. The list does not require any data that a person without legal capacity could not provide.

¹⁶² Law on Professional Rehabilitation and Employment of Persons with Disabilities, Article 24. Employers hiring between 20 and 49 people must employ at least one person with disability, those employing more than 50 people must employ two persons with disability, while for each additional 50 employees, one additional person with disability must be employed.

contribute towards the salaries of disabled persons who are employed in professional rehabilitation enterprises or they may enter into a cooperation contract with such an enterprise.¹⁶³ If employers fail to meet this requirement, they must pay fines into a state budget fund designated for persons with disabilities.¹⁶⁴

Protection and Prohibition of Discrimination

Interestingly, the Law on Professional Rehabilitation fails to define protection from harassment, forced and compulsory labour, redress of grievances, as well as labour and trade union rights. These issues are only covered by general laws: the Law on Prevention of Abuse at Workplace,¹⁶⁵ the Labour Law, and to some extent the Law on Prohibition of Discrimination.¹⁶⁶

The Labour Law bans direct and indirect discrimination in employment and work on the basis of several factors, including disability.¹⁶⁷ Discrimination is defined in more detail in the Law Against Discrimination of Persons with Disabilities,¹⁶⁸ which provides a higher standard of protection than the Labour Law. Article 21 of the Law against Discrimination of Persons with Disabilities prohibits employment and work discrimination in relation to disabled persons as well as persons engaged in assisting a disabled person on a long-term basis without compensation. This applies to all employed persons and those who are officially registered as jobseekers. The law also lists specific actions that constitute employment and work discrimination. These include a refusal to adapt the workplace so that a disabled person can work effectively if the costs are not borne by the employer or are not disproportionate to the benefit gained by hiring that person.¹⁶⁹ This provision of the law is an indication as to what the national legislation considers to be reasonable accommodation.

Special Forms of Employment

The Law on Professional Rehabilitation and Employment of Persons with Disabilities also defines various forms of employment for persons with disabilities. In addition to being employed under general or special conditions, both of which are considered open market employment, the law also prescribes special forms of employment and work engagement for persons with disabilities within framework of:

- enterprises for the professional rehabilitation and employment of persons with disabilities (EPR),
- social enterprises and organizations, and
- work centres.

Social enterprises and social organizations are profit entities (companies, enterprises) established for the purpose of meeting the socio-economic needs of persons with disabilities that employ at least one person with disability (Article 45), regardless of total number of employees. Part of such a company's profits must be used to integrate its disabled clients into the community, improve their living standards, working conditions, and work skills, and satisfy the needs of persons with disabilities. EPRs focused in particular on the work integration of persons with disabilities. These organizations have a license of the Ministry of Economy and Regional Development for employing a certain number of persons with disabilities and for engaging in their professional rehabilitation.¹⁷⁰

Based on the definitions contained in Article 43, work centres can be described as sheltered workshops in which users perform activities in segregated, isolated and strictly controlled conditions. The role of a work centre is to “ensure work engagement as a form of occupational therapeutic activity for those persons with disabilities who cannot be employed or to preserve their employment under both general or specific conditions, or whose working effectiveness is less than one third of a typical employee.” We should nevertheless emphasize that working at a work centre as a “long-term form of professional rehabilitation” (as described by the legislation) cannot be considered “work”.

¹⁶³ The Law on Professional Rehabilitation and Employment of Persons with Disabilities, Article 26 and 27.

¹⁶⁴ Ibid., Article 29.

¹⁶⁵ Official Gazette of the Republic of Serbia, No.36/2010, Law on Prevention of Abuse at Workplace.

¹⁶⁶ Official Gazette of the Republic of Serbia, No.22/2009, Law on Prohibition of Discrimination.

¹⁶⁷ Labour Law, Article 18.

¹⁶⁸ Official Gazette of the Republic of Serbia, No. 33/2006, Law against Discrimination of Persons with Disabilities.

¹⁶⁹ Ibid., Article 22, paragraph 4.

¹⁷⁰ The Law on Professional Rehabilitation and Employment of Persons with Disabilities, Article 35 through 42.

According to the World Health Organization rehabilitation is a process aimed at providing persons with disabilities with the tools they need to attain independence and self-determination.¹⁷¹ In this sense, rehabilitation is not a purpose in and of itself, but must serve to help people build skills with the aim of being included in the labour market under general or special conditions. The use of the phrase “long-term” implies that the purpose of rehabilitation is lost, which thus calls into doubt the work centres’ entire reason of existence. Furthermore, since there are no criteria as to who may be employed at EPRs, social enterprises or social organizations, we may ask whether persons with the lowest work capacity assessment may not find engagement somewhere other than work centres.

Persons with intellectual disabilities are often more capable of performing simple, repetitive tasks, sometimes with some form of support. If we assess their general working capability without taking into consideration the possibility of training and support for performing a specific job, there is a high likelihood that they will receive a poor work capacity assessment (i.e., working effectiveness of less than the one third of typical employees). With such an assessment grade, they cannot be employed on the open labour market despite the fact that there exist numerous jobs that can be performed by persons with intellectual disabilities. As a result, we are justifiably concerned that the law in its current form indirectly prevents persons with intellectual disabilities from being employed on the open market. Moreover, with the current wording of the law makes it is doubtful that persons with intellectual disabilities will have the opportunity to work even in certain special forms of employment.

Future Strategic Priorities

The Serbian government adopted the national strategy on employment for the 2011–2020 period in May 2011. The second strategic goal and priority is improving human capital and increasing social inclusion. The strategy recognizes persons with disabilities as a particularly vulnerable group on the labour market. It does not specifically refer to persons with intellectual disabilities or persons without legal capacity. Priorities for the employment of persons with disabilities include: training of employees of the National Employment Service for working with persons of low employability, forming a network of centres for the professional rehabilitation and employment of persons with disabilities within local NES offices, building capacities and improving the procedures of work capacity assessment commissions, and building the capacity of EPRs in order to make them the main carriers of professional rehabilitation.

¹⁷¹ For more information, see <http://www.who.int/topics/rehabilitation/en/>

PRACTICE

According to government reports,¹⁷² employment in the Republic of Serbia has been decreasing ever since the start of the financial crisis in 2008. An astonishing 41.2% of working-age individuals are categorized as inactive. The greatest growth in unemployment is among persons aged 25-34, with unemployment of young people in general being very pronounced and considerably higher than the general unemployment rate. The report also states that the crisis has additionally aggravated the situation of vulnerable groups, though it does not specifically mention persons with disabilities.¹⁷³

Employing Persons with Disabilities in Practice

In 2009, the total number of unemployed persons with disabilities registered with the National Employment Service was 22,023, of whom 32.5% were women. A total 11,360 persons with disabilities were covered by career management and counselling. In 2010, the total number of persons with disabilities registered with the National Employment Service was 20,312. In terms educational level, the largest group are persons with primary school education (more than 7,000 individuals).¹⁷⁴

According to another government report, since the new law came into effect (May 2009 to end of 2010), 5,558 persons with disabilities from NES records signed employment contracts.¹⁷⁵ At the same time, the number of persons with disabilities registered as unemployed with the NES did not decrease, because of new persons who submitted requests for work capacity assessments.¹⁷⁶

Based on recent studies of the employment of disabled persons in Serbia conducted by the Centre for Orientation of Society (COD) and the Belgrade Centre for Human Rights, we can conclude that the law is not much respected in practice.¹⁷⁷ The main findings show that in many cases employers opt to pay sanctions instead of employing disabled persons. This behaviour seems to have more to do with prejudice than with financial viability. For instance, the COD reports that some employers justify their decision by stating that they do not have any positions suitable for disabled persons.¹⁷⁸ Similarly, employers commonly do not employ disabled persons, but instead request work capacity assessments for persons already employed at the company.¹⁷⁹ Also, some employees try to manipulate the affirmative action measures by employing persons who are disabled “on paper” only in order to receive subsidies.¹⁸⁰ We frequently heard that employers are not familiar with disabilities and do not know about possibilities for employing disabled persons.¹⁸¹

In relation to the requirement to employ disabled persons, we should also mention that government agencies have been granted a moratorium for employing disabled persons under the quota system.¹⁸² Specifically, all direct and indirect recipients of funding from the state budget can meet their obligations under the quota system by contributing to the state budget fund for the salaries of disabled persons working at EPRs, improving working conditions, improving production and other purposes.¹⁸³ In this sense, the state has not only managed to circumvent its obligations as mandated by Article 27(g) of the CRPD, but it has also failed to set a positive example and motivate other

¹⁷² First National Report on Social Inclusion and Poverty Reduction in the Republic of Serbia 2008-2010, Government of the Republic of Serbia (March 2011), page 105-109.

¹⁷³ Ibid., “...particularly the young, persons without education, rural population, refugees and internally displaced persons on the labour market and Roma.”

¹⁷⁴ Ibid., 114-115.

¹⁷⁵ Draft initial report on implementation of the Convention on the Rights of Persons with Disabilities in the Republic of Serbia, Ministry of Human and Minority Rights, State Governance and Local Self-governance (December 2011), page 51, paragraph 300.

¹⁷⁶ Ibid.

¹⁷⁷ Loncar, Goran; Mihok, Zoltan; Grujić, Nikola; Sretenović, Aleksandra. 2011. Zapošljavanje osoba sa invaliditetom u Republici Srbiji, Centar za orijentaciju društva, Belgrade, page 35.

¹⁷⁸ Ibid., 34, 35, and 64.

¹⁷⁹ Ibid., 20, 26, 34, and 38.

¹⁸⁰ Ibid., 39.

¹⁸¹ Ibid., 42.

¹⁸² Due to rationalization measures based on the agreement with International Monetary Fund.

¹⁸³ Official Gazette of the Republic of Serbia No. 33/10 and 48/10, Rulebook on manner of monitoring completion of obligation to employ persons with disabilities and manner of proving that obligation, Article 8.

employers in the country. It is also doubtful whether these financial contributions will have any impact, given the relatively low number of EPRs and disabled persons working they.

Role of the National Employment Service: Work Capacity Assessments and Affirmative Action Measures

The National Employment Service is involved in activities related to employment, unemployment insurance, the realization of insurance rights in case of unemployment and other rights in accordance with the law, as well as maintaining an employment registry. It is also responsible for stimulating the employment of disabled persons through affirmative action measures. The NES coordinating body for all relevant activities and measures aimed at disabled persons is the Centre for Professional Rehabilitation and Employment of Persons with Disabilities.

One of the centre's most important activities is developing standards for work capacity assessment. From the introduction of work assessment capacity until December 2011, some 11,602 requests have been submitted to the NES and 10,056 first-instance decisions have been made, with 360 appeals filed against these first-instance decisions.¹⁸⁴

Work capacity assessment

Work capacity grade	# of persons	% of assessed persons
0 (no difficulties or barriers which impact work capacity)	738	7.4
1 (small difficulties or barriers which impact work under general conditions)	7,763	77.2
2 (significant difficulties or barriers which impact work under special conditions)	1,159	11.5
3 (complete or multiple difficulties or barriers which impact work under both general and special conditions)	396	3.9
TOTAL	10,056	100

The second-instance ruling is made by the Ministry of Economy and Regional Development's employment division, according to which the ministry received 300 appeals (as of 29 July 2011).¹⁸⁵ The reasons were mostly of a "health-related nature", with 114 appeals ruled on by that date. Of these, 73 NES decisions were overturned and 41 appeals were rejected. Unfortunately, we could not obtain any copies of the decisions, and could thus not familiarize ourselves with the first-instance and second-instance commissions' reasoning behind their work capacity decisions.

Another of the centre's significant roles is to publish calls for affirmative measures regarding the employment of persons with disabilities. In 2011, the NES published calls for the following measures for supporting the employment of disabled persons:

- Subsidies for opening new job positions;
- Subsidies for the self-employment of unemployed persons with disabilities,
- Organizing and implementing public works in which persons with disabilities will be engaged;
- Refunding salaries of persons who provide workplace assistance to persons with disabilities;
- Financing of workshops for persons with disabilities;
- Refunding expenses for workplace adaptation;
- Professional internship;
- Subsidies for employing disabled persons without prior work experience.

¹⁸⁴ Data obtained from the National Employment Service's response to a freedom of information request, 23 December 2011. (On file with the study's researchers.)

¹⁸⁵ Data obtained from the Ministry of Economy and Regional Development's request to a freedom of information request, 29 July 2011. (On file with the study's researchers.)

Number of affirmative measures requested and awarded¹⁸⁶

Measure/frequency	# of persons - requests	# of persons - decisions	# of persons – contracts
Subsidies for opening new job positions	330	239	222
Subsidies for self-employment	243	190	177
Public works	5,215	1,321	1,279
Refunding salaries of assistants	38	19	19
Workshops for disabled persons	22	1	1
Refunding expenses for work-place adaptations	27	18	16
Professional internship	65	57	46
Subsidies for employing persons with disabilities without work experience	338	278	278
TOTAL	6,278	2,123	2,038

Importunately, there is no disaggregated data on the type of disability. The NES does not keep records on employment according to persons with physical, sensory, intellectual, psychosocial, or other disabilities.¹⁸⁷ Furthermore, the NES does not have any data on the type of disability of persons who underwent a work capacity assessment, nor of persons with disabilities who were included in affirmative action measures and NES programs. The same applies the legal capacity of persons who are in the registry. This is strange, as it provides an incomplete picture of the employment of disabled persons in the country. We all know that people with intellectual disabilities face different problems and require different forms of assistance in order to successfully perform their work-related duties than people in wheelchairs or with impaired vision. As a result, we are legitimately concerned as to the manner in which the relevant authorities are designing and implementing affirmative action measures. Consequently, despite the significant volume of existing information on the employment of disabled persons, we cannot reach any final conclusions as to the impact of the law and of other measures for employing persons with intellectual disabilities.

Employment on the Open Labour Market

We talked to Delhaize,¹⁸⁸ one of the largest private employers on the Serbian market, about their views on and experiences with hiring persons with intellectual disabilities.¹⁸⁹ Out of more than 200 employees with disabilities, more than 20 have intellectual disabilities. Their job positions include shop merchandise display, storehouse work, and assistant positions in retail sales. All employees are hired under an employment contract and undergo theoretical as well as practical on-the-job training for their specific job position. The employees' supervisors and immediate colleagues are trained in order to raise their awareness and so that they can successfully communicate with their future colleagues. Each case is examined individually with a view to the needed support – personal assistance, adaptations to tools or equipment, working hours, shifts etc. A minority of employees with

¹⁸⁶ Data obtained from the response of the National Employment Service to the request for information of public benefit, 23 December 2011. (On file with researchers.)

¹⁸⁷ Response of the National Employment Service to the request for information of public benefit, 23 December 2011. (On file with researchers.) Also, interview with Director of Centre for Employment and Professional Rehabilitation of Persons with Disabilities, 12 September 2011.

¹⁸⁸ Interview with Milica Sretić, Coordinator for Recruitment and Selection, Delhaize Serbia, 6 December 2011.

¹⁸⁹ The questionnaire stressed that persons with autism should also be included in the answers. The overview of results includes persons with autism in final data; whenever the text refers to persons with intellectual disabilities, this is inclusive of persons with autism.

intellectual disabilities (four) need additional support and work with a supervisor, while all the others work independently. According to the human resources department, the company's experience in employing persons with intellectual disabilities has been positive:

"[They] are punctual, hard-working and dedicated employees, and are happy to have the opportunity to show and improve their potential in a working environment. They are well accepted within the team, and express their satisfaction at having work commitments, being able to contribute to the team on a daily basis, and having the opportunity to become more independent. Because of the high pace of retail sales and customer contact, several cases required a longer adjustment period, but with the goodwill and patience of the new employees, their families, the human resource staff and other colleagues, the adjustment was successful."

In the company's experience, the new legal regulations brought assurance and administrative ease in employment of persons with disabilities. Yet, according to them the main obstacle to employing persons with intellectual disabilities is that those who do not have legal capacity can only be included under the work engagement modality, but not employed under work contract (thus not being able to receive any compensation/salary for their work). This causes problems to potential workers as well as to employers. Additionally, their view is that more awareness through positive examples is needed on contributions, specificities and value of persons with intellectual disabilities in our immediate surrounding and in open market.

Employment in Sheltered Jobs

As previously explained, the Law on Professional Rehabilitation and Employment of Persons with Disabilities specifies three forms of employment for persons with disabilities outside the open market: enterprises for the professional rehabilitation and employment of persons with disabilities (EPR), social enterprises/organizations, and work centres. The rulebooks for the establishment and operation of the two latter are still being developed, meaning that, legally speaking, these forms of employment do not yet exist.¹⁹⁰

For this reason, our survey focused solely on EPRs, which, as already noted, are the strategic focus for the government's future capacity building efforts. In a survey sent to all existing EPRs (43 were in operation at the time of the survey¹⁹¹), 24 (55.8%) sent back a completed questionnaire. Based on their responses, we were able to reach several conclusions regarding the employment of persons with intellectual disabilities in special forms of work.

Employed at EPRs according to type of disability

Frequency/ Disability	Intellectual disabilities	Psycho- social disabili- ties	Hearing impair- ment	Sight impair- ment	Physical disabili- ties	Vocal- speech commu- nication disabili- ties	Chronic ill- nesses	Multiple disabili- ties	Total
Number of cases	388	122	234	22	55	9	146	39	1,015
Percentages	38.2	12.0	23.1	2.2	5.4	0.9	14.4	3.8	100

Based on these responses, we may conclude that persons with intellectual disabilities constitute a little more than one third of disabled individuals employed in this manner. When asked for additional information, not all respondents (EPRs) provided complete data. Given that all the information requested should be known to the employer, we presume that the questions were left unanswered because it was too difficult or time-consuming for the employers to collect this data. The analysis treats such responses as "unknown".

¹⁹⁰ Interviews with representatives of the Ministry of Economy and Regional Development and Centre for Professional Rehabilitation of Persons with Disabilities, 8 July 2011 and 12 September 2011.

¹⁹¹ September 2011, contact list received from the Ministry of Economy and Regional Development.

Employed at EPRs according to education completed

Cases/ education	No formal education	Completed primary education*	Completed secondary education*	Completed higher or high educa- tion	Unknown	Total	Special education
# of employ- ees with intellectual disabilities	8	120 (91)	151 (134)	0	109	388	225
% of total employees with intellectual disabilities	2.1%	30.9% (23.4%)	38.9% (34.5%)	0%	28.1%	100%	58.0%

* Special education

The vast majority (at least 70%) of these employees were included in some form of education, which is to say that persons with intellectual disabilities who were/are excluded from education are not being employed even in sheltered work.

Employed at EPRs according to assessed work capacity (AWC)

Employed / assessment	AWC 0	AWC 1	AWC 2	AWC 3	Work capacity not assessed	Unknown	Total
# of employees with intellectual disabilities	1	22	4	0	224	137	388
% of total employees with intellectual disabilities	0.3%	5.7%	1.1%	0%	57.7%	35.3%	100%

A large majority of persons with intellectual disabilities did not undergo work capacity assessment under the new law. This may indicate that they were not recently employed, but have been with the EPR since before the enactment of the new law. Out of the 27 who underwent the assessment, 23 were assessed as being able to find employment on the open market.

Employed at EPRs according to legal capacity

Employed/status	Fully deprived of legal capacity (plenary guardian- ship)	Partially deprived of legal capacity (partial guardian- ship)	Legal capac- ity preserved	Unknown	Total
# of employees with intellectual disabilities	0	113	141	134	388
% of total employees with intellectual disabilities	0%	29.1%	36.4%	34.5%	100%

One important goal was to determine the legal capacity of employed persons with intellectual disabilities. As can be seen, not a single fully deprived person is employed, which supports the conclusion that persons without legal capacity cannot be employed even in sheltered workplaces. A significant number of employees were partially deprived of legal capacity, but presumably the court left their employment rights intact.

Prospects for employees and users of professional rehabilitation at EPRs

Opportunities for professional advancement			Individual plans for users and employees			Employment on the open market		
Yes	No	Unknow	Yes	No	Unknow	Yes	No	Unknow
18	3	3	4	17	3	8	12	4
75%	12.5%	12.5%	16.7%	70.8%	12.5%	33.3%	50%	16.7%

It is also worth noting that while 75% of EPRs claim that their enterprise offers opportunities for professional advancement and only 12.5% report that they do not offer such opportunities (with the same number not answering the question), only 17% stated that they had developed individual plans for their employees. Furthermore, 50% of EPRs say that none of their employees or users of professional rehabilitation services was employed on the open market. A total of 17 employees or users of services from the eight EPRs found employment on the open market. This is a particularly low number, considering that the aim of professional rehabilitation is the individuals' inclusion in the regular labour force. What is more, we should emphasize that these data relate to all of employees and users of the EPRs' professional rehabilitation services, and not only to employees and users with intellectual disabilities.

Opinions for the employment of persons with intellectual disabilities – Multiple answers possible

Where they should be employed				Where they have a chance of being employed			
Open market	Sheltered workshops	Both	Nowhere	Open market	Sheltered workshops	Both	Nowhere
0	8	17	0	1	14	9	3
0%	33.3%	70.8%	0%	4.2%	58.3%	37.5%	12.5%

Decision-making regarding the employment of persons with intellectual disabilities

Who should be involved in deciding on where and how persons with intellectual disabilities are employed?						Who should make the final decision on where and how persons with intellectual disabilities are employed?					
Person him/herself	Employer	NES	Assessment commission	Parents / Guardians	Legislation	Person him/herself	Employer	NES	Assessment commission	Parents / Guardians	Legislation
17	17	17	23	14	10	14	11	7	18	7	5
70.8%	70.8%	70.8%	95.8%	58.3%	41.7%	58.3%	45.8%	29.2%	75%	29.2%	20.8%

One interesting fact is that the EPRs expressed a great amount of confidence in the work capacity assessment commissions and in the opinions issued by these commissions, even though their previous answers (specifically, the fact that only very few persons with intellectual disabilities had undergone a work capacity assessment) indicate that they have little experience with these commissions. Also, most of these employers and providers of professional rehabilitation services do not consider that decisions should be made through legislation. In other words, they feel that a law that prescribes

in advance that some persons' working activities should be limited to special forms of employment (sheltered workplaces) is unfair or not necessary. Finally, even though a large majority of EPRs feel that disabled persons should be involved in deciding on their employment and a smaller majority believes that the person should make the final decision, the figures in the table above continues to reflect the old paternalism according to which decisions related to person with intellectual disabilities should be made by others.

Thinking outside the box:

How can Article 27 of the CRPD be realized for adults with intellectual disabilities?

Nasa kuca (Our House) is an association founded by parents of young adults with intellectual disabilities. It runs a Day Centre that is visited by ten young men with disabilities aged 20+ a day. The centre work on developing social skills by widening its clients' network of friends and acquaintances. Each user has an individual support plan created in accordance with his needs and interests. The centre's users are people who are considered unemployable because they were excluded from the education system. As a result, they lack knowledge and skills and cannot find work on the open labour market. Moreover, most users have been deprived of legal capacity, which makes it even more impossible for them to find a job.

After unsuccessful attempts at helping their users find employment on the open labour market, the Nasa kuca support team decided to start its own business. In this way, the association's users had a chance for find professional fulfilment and could acquire skills and knowledge that might eventually prepare them for entering the open market. The association purchased a machine for producing paper bags, adapted the workplace, and began production. For the young men at the centre, this was the first real, paid job. They received training with the help of the support team, at first in just one part of paper bag production process. Over time, they were trained to work in the other parts of the production process as well. The fact that they are paid for their work has been an extremely important and simulating factor.

This positive experience also encouraged the support team to expand operations and to enable the users to work in a more open environment. With cooperation from the local town hall, they established an affordable "Meals on Wheels" meal and medication delivery service for elderly persons in need of care and assistance. This service offers jobs at the easy-to-use touch screen cash register, in food packaging and in food delivery. Since most users are not familiar with money and/or cannot do math, a special software program was developed in order to help them work with bills and coins regardless of their skills or weaknesses.

This service is significant in several ways: it raises the quality of life for elderly persons and their families and provides new experiences and new working opportunities for young people with intellectual disabilities. This model is a form of social entrepreneurship that may well represent a sustainable answer to the obstacles to employing persons with intellectual disabilities under the current conditions. Other associations for persons with intellectual disabilities also can create similar assistance employment programs, thus contributing to this population's independence and sense of belonging. This possibility is embedded in the Law on Associations of Citizens¹⁹², which allows associations to engage in certain economic activities, the profit from which must be used for achieving the association's goals and ensuring the sustainability of its activities. We must stress that the role of the government is to provide support to initiatives that enable the most marginalized populations to realize their right to work.

¹⁹² Official Gazette of the Republic of Serbia, No. 51/2009 and 99/2011, Law on Associations of Citizens.

Conclusion

Despite the hoped-for advances resulting from the new law on employment of persons with disabilities, its actual impact so far would appear to be quite limited. Moreover, persons with intellectual disabilities are apparently being placed into more disadvantaged position than other potential beneficiaries of the law. The Law on Professional Rehabilitation and Employment of Persons with Disabilities contains two major shortcomings. Firstly, it does not address the status of persons without legal capacity despite the fact that a significant number of persons with intellectual and psychosocial disabilities have been deprived of legal capacity. Secondly, work capacity assessments are devised in a way that limits the effectiveness of affirmative action measures for employing persons with disabilities. In addition, assessments take place in an artificial environment in which the persons concerned, especially those with communication difficulties, cannot express their full potential and skills.

Affirmative action measures should include a system of individually tailored support programmes aimed at creating favourable conditions for specific jobs. This should be a continuous process, particularly because a person's need for supports changes as he or she develops through social and workplace interactions. The current solution provided by the law prescribes assessments on the basis of a significantly differing rationale, thus directly endangering the right to work of people who have not had a chance to acquire skills and education as a result of their social and educational exclusion.

Recommendations:

- Enact the legislative changes necessary for ensuring that persons deprived of legal capacity will regain their right to work and employment;
- Ensure that persons who are deprived of legal capacity are not invisible for the National Employment Service and that they can register as unemployed and receive unemployment insurance and benefits, and can benefit from positive employment measures;
- Keep records that provide a full reflection of disabilities while ensuring that no disability-specific group of persons remains outside the scope of positive employment measures;
- Reform the work capacity assessment process; instead of evaluating a person's work capacity, the commission should be charged with evaluating the support and workplace adaptation required for a particular person to perform a particular job;
- Ensure that affirmative action measures intended to help disabled persons find employment on the open labour market are directed equally at persons with varying kinds of disabilities (intellectual and other);
- Ensure greater transparency of the flow of the budgetary funds received from employer penalties paid for not hiring persons with disabilities;
- Raise awareness among employers, including Enterprises for the Professional Rehabilitation of Persons with Disabilities, regarding disabled persons' right to work, including persons with intellectual disabilities;
- Support creative initiatives developed by organizations involved in hiring disadvantaged persons with disabilities.

ANNEX I

Methodology

1. Secondary research: analysis of publicly available documents;

2. Freedom of information requests were addressed to:

- All municipal courts (34) and high courts (26) in Serbia (December 2010), whom we asked to provide statistics and copies of all decisions regarding legal capacity deprivation and reinstatement, and the extension and cancellation of parental rights. We requested copies of the relevant decisions for the period from 2008 to 2010. Our analysis involved all of the delivered decisions, thus ensuring a sample of more than 1,000 cases (997 lower courts and 68 higher courts). The 994 municipal court decisions served as a primary sample, while the higher court decisions were analysed separately and only qualitatively because of the different nature of the procedure. The examination included an analysis according to criteria that had been established in advance.
- National Employment Service (November 2011), who we asked to provide the following information: number and results of submitted requests for work capacity assessments, assessed work capacity of persons with intellectual disabilities, assessed work capacity of persons without legal capacity, the number and type of active measures implemented, the number of persons with intellectual disabilities benefiting from active measures, the number of persons without legal capacity benefiting from active measures.
- Ministry of Economy and Regional Development (July 2011), who we asked for information on the number, nature and outcome of appeals of first-instance decisions on work capacity.
- Fund for Social Innovation (FSI) (2010), whom we asked for information on funded projects whose beneficiaries were children and adults with intellectual disabilities: amount awarded, project description, project duration.

3. Semi-structured interviews with:

- Officials from the Ministry of Labour and Social Policy (2010) for the purpose of the “Donor Accountability – Implementation” project of Article 32 of the Convention on the Rights of Persons with Disabilities in Serbia;
- Officials from the Ministry of Economy and Regional Development (2011);
- Centre for the Professional Rehabilitation and Employment of Persons with Disabilities (2011); and
- Coordinator for Recruitment and Selection, Delhaize Serbia (2011).

4. Focus groups with parents/guardians of children and adults with intellectual disabilities (including one young adult with intellectual disabilities).

Three focus groups were conducted in October and November 2011 on the topic of community services. One was conducted in the small town of Vrsac, one in the medium-sized town of Leskovac, and one in the capital, Belgrade (all consisted of 4-5 participants). The participants were age-diverse family members with different support needs and different life experiences.

5. Questionnaires (all were sent out during 2011):

- Children with difficulties in the education system in Serbia [*Deca sa teskocama u obrazovnom sistemu u Srbiji*] was developed for primary schools throughout Serbia. The sample was randomly selected from contacts available from the website of the Ministry of Education. These included: 544 regular schools and all 37 special schools (a total of 581 regular and special schools). The questionnaire, which requested information for 2010/2011, was sent by mail and e-mail and was posted online. A total of 123 schools (113 regular and 10 special schools) replied with the information requested.

- The ***Questionnaire for parents/guardians of school-aged children with intellectual disabilities and autism spectrum disorder [Upitnik za roditelje/staratelje skolske dece sa intelektualnim teskocama i smetnjama iz spektra autizma]*** was developed for parents or guardians of children with intellectual disabilities. Participation was anonymous. The questionnaire was posted online and was distributed through targeted e-mails and social networks. A total of 33 questionnaires were received, 25 of which were filled out by our target group – parents of children with intellectual disabilities. Eight questionnaires came from parents of children with physical disabilities and dyslexia. These were analysed separately, since the type of support required by students with intellectual difficulties differs from the type of support required by children with other type of learning difficulties. The results in this report refer only to the target group – children with intellectual disabilities and autism (25). Geographically, the results came from Belgrade and six other towns throughout Serbia. Out of 25 children with intellectual disabilities, 19 were enrolled in regular school and 6 were in special school.
- ***General questionnaire for institutions of social protection [Opsti upitnik za ustanove socijalne zastite]***. This questionnaire was developed for all residential institutions in Serbia that were home to children with developmental difficulties. It was sent to following institutions: Sremcica Home, Belgrade; Veternik Home, Novi Sad; Centre for the Protection of Infants, Children and Youth, Belgrade; Zvecanska Unit for Placement with Intensive Support; Kolevka Home, Subotica; Home for Persons with Autism, Belgrade; Dr. Nikola Sumenkovic Home, Starnica; and Kulina Home. We received responses from all institutions.
- ***Employment of persons with intellectual disabilities and autism [Zaposljavanje osoba sa intelektualnim teskocama i autizmom]***; sent out to all existing enterprises for the professional rehabilitation and employment of persons with disabilities. According to the contact list received from the Ministry of Economy and Regional Development as of September 2011, there were 43 enterprises in operation. We received responses from 24 enterprises (55.8%).

CONCLUSION

The United Nations Convention on the Rights of People with Disabilities (CRPD) establishes the duty of member states to adhere to international standards of respecting, protecting and promoting the rights of people with disabilities. Bosnia and Herzegovina and Serbia are ratifying members of the CRPD; Kosovo still faces political barriers to ratification. The European Union's ratification of this human rights document represents a precedent in international human rights law. With the adoption of international standards, including the CRPD, came the realization that human rights apply to people with intellectual disabilities as well, and that the government's obligation must be translated into positive measures for ensuring that they can live their life on equal basis with others.

Our survey of law and practice in these three countries provided evidence that certain initial steps have been taken by the governments, primarily as relates to the adoption of new laws. For instance, laws mandating inclusive education and aimed at stimulating the employment of people with disabilities are a valuable step towards achieving equality for people with disabilities. Still, the actual practice shows an insufficient shift in attitudes among state authorities and professionals, and a lack of commitment to implementing the laws.

Another point to be stressed is that people with intellectual disabilities are often overlooked during the process of formulating laws and policies aimed at improving the status of people with disabilities, and this situation helps to preserve the existing barriers. Most noted in this sense is a failure to switch from a medical to a social paradigm and the continued habit of evaluating a person's capabilities instead of assessing the support he needs in particular life or work situations. Deprivation of legal capacity is the primary example of this failure to lift prejudicial and legal barriers based on medical diagnosis. Although the countries realize that this approach is in non-compliance with the CRPD, they continue to deprive people of their ability to decide and act, further adding to the restrictions faced by people with intellectual disabilities. In many cases, deprivation of legal capacity results in institutional placement, sealing the fate of people with intellectual disabilities: lifelong institutionalisation. In conclusion, we may state that although the law has been improved in some aspects, generally speaking it remains a barrier to the social inclusion of people with intellectual disabilities.

Furthermore, the dominant form of care for people with intellectual disabilities in all three countries remains institutional care. There still are no specific plans or steps for de-institutionalisation. The reintegration of people living in institutions into family or community life is extremely rare, and life in institutions does not stimulate the residents to build the skills necessary for independent living. The creation of in-community support services for independent community living is still in its early phases, with a chronic lack of much-needed versatile and good services.

The educational system shows promising signs of being on track to enabling the inclusion of all children. All three countries have enacted standards for enabling children with intellectual disabilities to attend mainstream schools. In practice, however, the implementation of inclusive education is often slow and disoriented. Only a fraction of children with disabilities can attend education, and a great number of them continue to be left outside the educational system. A shift towards inclusive education must be the uncompromising priority of all the governments, and must be achieved by removing all barriers and providing the necessary teaching skills and didactic materials for offering a stimulating environment for all children.

Within the context of their weak economies and the enduring economic crisis, the job market in all three countries is extremely limited, and the number of jobs available continues to decline in comparison to the number of job seekers. Access to the job market is practically nonexistent for people with intellectual disabilities. People who have been deprived of legal capacity do not have the legal right to establish contractual agreements, an issue that has not been addressed by special laws regulating the employment of people with disabilities and definitely acts as a demotivating factor for this population when trying to find employment. Furthermore, no quota system for hiring people with disabilities has been implemented, although it is required by law.

There is a considerable failure in attaining all of the rights that were examined by this study – legal capacity, community living, education and employment. It goes to say that disability rights are still not being treated as an integral component of universal human rights, and governments appear hesitant in implementing the genuine changes that such treatment requires.

One encouraging fact is that we can see positive examples of good practice everywhere in the region – as illustrated throughout this report. These examples, usually initiated and promoted by civil society, have the potential of being replicated and systemized, but also of breaking through the prejudice that people with intellectual disabilities are uneducable, incompetent and unworthy in society. Civil society remains a crucial resource that can serve as a catalyst for positive change in each country, and for sharing experiences among the three countries for overcoming current challenges. In this respect, civil society, as it often does, can serve as a connecting bridge for re-establishing communication channels between governments in the region, particularly since these channels have been damaged and are almost exclusively dedicated to political topics.

The first issue that needs to be addressed is to focus the governments' energies at the country level towards dealing exclusively with bridging the gap between the legislative framework and practical aspect implementation of UN CRPD. The governments of all three countries must show a readiness and willingness to undertaking the necessary steps for the social inclusion of people with disabilities within the community. This naturally requires having a clear understanding of what social services can promote independent living, but it also has wider implications – from establishing inclusive kindergartens, schools, services and job-markets to removing the legal obstacles preventing adults with disabilities from fully participating in society.

COMMON RECOMMENDATIONS FOR THE EU

- Make sure that the issue of respecting, protecting and promoting the rights of people with disabilities remains high on the agenda of EU integration negotiations with all potential member states;
- Terminate funding or support for building or renovating new institutional care facilities for people with disabilities; make it explicit in regulations that the Instrument of Pre-Accession cannot be used in order to provide segregated care for persons with disabilities;
- Assist the governments in initiating the necessary changes in legislative infrastructure regarding the issue of legal capacity deprivation, support mechanisms that will serve as safeguards in the justice system, and promote facilitative measures for people with disabilities during decision-making processes;
- Encourage governments to explore alternative paradigms to institutional life by examining various community-based solutions that allow for the supported and independent living of all people with intellectual disabilities;
- Support regional networks of civic society organizations and non-governmental organizations for and by people with disabilities that can share experiences and best practice related to the issue of disabilities;
- Fund projects that build partnerships with local governments and civil society organizations with the aim of enhancing job opportunities for people with disabilities;

COMMON RECOMMENDATIONS FOR THE COUNTRY GOVERNMENTS

- Establish focal points in the political structure for ensuring the full implementation of obligations deriving from the United Nations Convention on the Rights of People with Disabilities, pursuant to its Article 33;
- Involve people with disabilities and people with intellectual and psychosocial disabilities in any decision-making processes affecting them at the national or local level;
- Abandon the medical model when addressing the issue of disability in law and policy, in favour of the social inclusion model;
- As a matter of urgency, instigate the necessary legislative changes regarding adults' legal in order to ensure that any deprivation of legal capacity remains disability-neutral:
 - o Amend the legislation enforcing the use of safeguards,
 - o Plan regular periodic re-assessments of all court decisions related to the deprivation of legal capacity,
 - o Ensure quality legal representation,
 - o Enforce the use of the least restrictive measures,
 - o Eventually remove the possibility for deprivation of legal capacity;
- Investigate mechanisms for overcoming rigid substitute decision-making in order to develop appropriate mechanisms for supported-decision making; include people with intellectual and psychosocial disabilities in this process;
- Improve data collection pertaining to the situation and needs of people with disabilities in all public services; where required, disaggregate data according to the type of disability;
- Ensure the implementation of disability-related legislation:
 - o Enable all children to attend mainstream schools and to receive the support they need in order to make optimum use of their physical and mental abilities,
 - o Improve the skills of teaching staff and ensure sufficient support personnel in mainstream schools and kindergartens,
 - o Ensure the implementation of the quota system in employment, in both the public and private sector,
 - o Seek accountability from all stakeholders who are responsible for the social inclusion of people with disabilities;
- Develop and enforce professional standards that will govern the conduct of service providers, ensuring that these standards are guided by the principles of the CRPD;
- Develop a de-institutionalisation plan with concrete steps, specific deadlines and allocated budgets – express a clear commitment to closing long-term residential institutions in favour of community placement and supported living for all people with intellectual disabilities;
- Build partnerships with civil society organizations and consult with organizations for and by people with disabilities in all discussions pertaining to the issue of disability;
- Enhance regional cooperation in the field of disability – cooperate with governments in the region in order to improve the social inclusion of people with disabilities by sharing experiences and best practices and utilizing the potential for joint initiatives.

RECOMMENDATIONS FOR THE GOVERNMENT OF BOSNIA AND HERZEGOVINA

Equal Recognition before the Law

- End the process of legal capacity deprivation;
- Promote the independence and dignity of people with intellectual disabilities by introducing less restrictive measures in the legal capacity deprivation process and providing support in decision-making processes;
- Review all court decisions of legal capacity deprivation,
 - o Restore full or partial legal capacity in all cases in which expert testimony determines the need for and merits of doing so,
 - o Establish special departments in the justice system for dealing with the process of legal deprivation and the reinstatement of legal capacity, employing experts that are free of any conflict of interest;
- Encourage the active participation of civil society organizations in the legal capacity deprivation process and in establishing a system for the supported decision-making for people with intellectual disabilities;
- Establish a system for monitoring and recording the number and details of court hearings related to legal capacity assessment;
- Provide qualitative legal representation of and counselling for people with intellectual disabilities and their families;
- Scrutinize the performance of and establish a quality control mechanism for the Institute for Medical Expertise of Health Conditions in Sarajevo;
- Raise awareness regarding the rights of people with disabilities.

Living Independently and Inclusion in the Community

- Promote independent living and inclusion in the community for all people with disabilities, enabling each person to choose under what conditions, where and with whom they want to life;
- Establish and implement a strategy for replacing institutional care with independent or supported living in the community,
 - o Test alternatives to institutional life and initiatives for preventing institutionalisation,
 - o Develop a detailed action plan, and find the necessary resources for implementing the process of de-institutionalisation;
- Terminate funding and support for building or renovating new institutional care facilities for people with disabilities; adopt explicit legislation that government funds must not be used for segregated care for persons with disabilities;
- Improve cooperation between cantons by establishing cantonal bodies that will supervise the implementation of governing policies on social care,
 - o Strategy for Equalisation of Possibilities of Persons with Disabilities FB&H 2011-2015 must be accompanied by planned activities schedule at the cantonal level,
 - o Establish centres at the cantonal level that will instigate and monitor the process of institution transformation;
- Develop service quality standards and monitor implementation in practice,
 - o Provide training to service providers;
- Raise awareness among people with disabilities regarding human rights and how to attain those rights.

Education

- Identify and provide support to children with disabilities from the earliest stages of their disability, through a myriad of institutions and resource centres offering services in the educational, social and healthcare sectors,
 - o Meet the needs and utilize the potential of every child,
 - o Match the needs of children with disabilities with available resources;
- Establish and enforce mechanisms for supervising the inclusive education of children with disabilities in mainstream education,
 - o Improve the teaching staff's skills for working with children with disabilities by providing training in implementing the qualitative inclusive education process, developing individual programs and utilizing parents as a teaching resource,
 - o Increase the ability of future teaching staff to work with children with disabilities,
 - o Provide appropriate and timely education for all children with disabilities living in social care institutions;
- Increase parents' ability to work with children with disabilities, through various counselling and training services;
- Transform special schools into resource centres for assistance in classes;
- Enhance the role of professional mobile teams that will provide additional support depending on a student's individual needs;
- Develop a support system for children and people with disabilities enrolled in school,
 - o Provide the necessary assistance services tailored to the students' individual needs, such as teaching assistants, personal assistants, educational rehabilitation or peer support;
- Ensure continuous and sufficient funding for inclusive education;
- Establish cooperation with civil society organizations within programs and projects aimed at improving the quality of inclusive education.

Work and Employment

- Assets accumulated in the Fund for Professional Rehabilitation and Employment of Persons with Disabilities in FB&H must be directed and distributed to employment without discriminating by the type of disability,
 - o Gear the fund's activities towards developing incentives for employment, self-employment and remaining employed, and towards making progress in this area;
- Establish retraining and employment agencies within the relevant ministries that will cooperate with the Fund, educational institutions and the labour market;
- Ensure the implementation of the Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in FB&H,
 - o Organize the continuous monitoring of measures aimed at the employment of people with disabilities according to the quota system required by law;
- Develop a data collection system for keeping track of the employment status of people with disabilities;
- Establish cooperation between educational institutions and the labour market with the aim of identifying professions that are aligned with the needs and abilities of persons with disabilities,
 - o Develop programs for professional retraining, employment and specialization, with the aim of increasing access to life-long learning programs for persons with disabilities;
- Raise awareness among employers regarding the rights and obligations contained in the Law on Professional Rehabilitation, Retraining and Employment of Persons with Disabilities in FB&H, as well as the potential and skills offered by people with disabilities on the open labour market;
- Encourage people with disabilities to become actively involved in the labour market.

RECOMMENDATIONS FOR THE GOVERNMENT OF KOSOVO

Equality Recognition before the Law

- Establish an independent body for developing mechanisms and monitoring progress towards meeting the standards delineated in the CRPD;
- Review the legal infrastructure in all predispositions governing the issue of legal capacity deprivation,
 - o Amend the Law on Non-Contested Procedure, removing the current restrictions posed by the possibility of enforcing legal capacity deprivation;
- Judges in the court system must be trained to exercise the option of facilitating a decision-making process for the people whose legal capacity is being assessed, instead of restricting them to the fullest possible extent in making decisions affecting their personal life;
- The justice system must give priority to other legally-binding documents that promote equal treatment for all people before the law,
 - o The judicial system must maintain a fair balance of legislation when initiating hearings related to legal capacity deprivation,
 - o The promotion and protection of human rights for all people must be an uncompromising priority;
- Organizations for people with disabilities and civic society organizations should be more active in promoting the right of people with disabilities to decide on matters that affect them,
 - o Civil society organizations must be given support in capacity building, increasing the resources for generating operational funds, sustainability, and advocacy campaigns.

Living Independently and Inclusion in the Community

- Improve the legal infrastructure and policies, with the aim of promoting independent living in a community setting,
 - o Reaffirm the willingness to do so by producing action-oriented strategies and developing capacities for full engagement towards independent community life;
- Reduced the number of service providers based on the medical approach in favour of increasing capacities for socio- and psycho-therapeutic treatment;
- Set a realistic and definitive time-schedule for closing the Special Institute in Shtime (SISH),
 - o The Ministry of Labour and Social Welfare must reallocate available funds currently dedicated to the building and renovating residential institutions towards exploring new inclusive approaches that will ensure the full integration of people with intellectual disabilities into the community while ensuring that they are no longer isolated and segregated as they currently are,
 - o De-institutionalisation and supported living and independent living plans and initiatives must be discussed publicly and with civic society, including residents and organizations for people with disabilities, who must be considered to be crucial and indispensable stakeholders in this process,
 - o The promotion of residents' independence and self-determination should be an imperative and they must be physically integrated within the community. The option of placing residents into small groups living independently in private houses in the community should serve as a basis for possible further modifications;
- Policy makers in the field of social care and service providers should be offered training on human rights and disabilities,
 - o Mechanisms must be put in place for enforcing the proper conduct of service providers, with an emphasis on the need to protect and promote the positive, dignified and humane treatment of people with intellectual disabilities;
- Adjust the organization of community-based homes to reflect their mission,

- o Community-based homes must provide care that utilizes the residents' physical, mental, social and professional abilities, and must be aimed at their future reintegration and independent community living.

Education

- Develop strategies and intervention plans for improve results in the field of inclusive education;
- Remove legal regulations that lead to the segregation of children with disabilities, restrict their participation in the decision-making process and prevent equal treatment as compared to other children;
- Provide the resources necessary for children with disabilities to receive education,
 - o Provide the necessary resources for school authorities to enrol children with disabilities,
 - o Ensure that school authorities enrol all children with disabilities that wish to do so,
 - o The training of teachers in the field of inclusive education must be mandatory, along with continuous efforts at developing the capacities for working with children with disabilities,
 - o Undertake initiatives to increase the number of children with disabilities enrolled in school,
 - o Make sure that all children with special needs enrolled in education have an Individual Education Plan, and improve teachers' abilities to develop and implement these plans;
- Address the needs and improve the skills of teachers who work with children with disabilities by making better and increased use of travelling teachers employed by the Resource Centres;
- Convenient and safe transportation for children with disabilities must be universal, free and sustainable;
- Municipal evaluation commissions should be formed and become fully functional as soon as possible,
 - o The work of these evaluation commissions must bear in mind the principles of inclusive education, with the team's expertise focused on developing teaching methods that will yield the best results for each individual case,
 - o Coordinate the efforts of the municipal evaluation commissions and teachers working with children with disabilities to ensure that the utmost effort is being expended for meeting the needs of students with special needs.

Work and Employment

- Improve data collection on the abilities, predispositions and potential of people with disabilities to access the labour market;
- Enlist all unemployed people with intellectual disabilities as job-seekers and undertake activities to increase their participation in the labour market;
- Centres for vocational training should offer more programs that respond more accurately to the needs of people with disabilities, and should initiate programs that might generate more employment opportunities;
- Inform the private sector about the training opportunities provided by centres for vocational rehabilitation from which they can benefit by hiring employees who have been trained to perform the tasks they require;
- Enforce the quota system for employment in the public and private sector;
- Establish cooperation with organizations for the rights of people with disabilities, and use best practices from employment in the implemented projects.

RECOMMENDATIONS FOR THE GOVERNMENT OF SERBIA

Equal Recognition before the Law

- Gear legislation and public policy towards creating diverse options so that opportunities for growth and development are afforded to all persons with disabilities, including opportunities for restoring or promoting the capacity to make decisions;
- Shift the approach in the field of legal capacity from the medical to the social model of disability by devising a new legislative framework;
- Amend the Family Law and Law on Non-Contested Procedure so that instead of being deprived of legal capacity, persons with intellectual or other disabilities are given adequate support (such as advance planning, the right to accessible information, reasonable accommodations, legal support, supported decision-making, facilitated decision-making and co-decision-making) when making decisions that affect their life;
- Amend all other laws that restrict the rights of persons without legal capacity;
- Until a comprehensive legal reform can be implemented, court rulings should limit persons' legal capacity to the least possible extent and should work towards developing an individual approach to assessing the challenges faced by disabled people:
 - o Use existing procedural guarantees and hear the person, be present at the experts' examinations of persons, make efforts to communicate with persons in simple language or use other means of communication if persons are non-verbal, and establish visual contact with every person;
 - o Pay special attention to the quality of legal representation of persons before the court, and assess whether a conflict of interest may exist between a person and their temporary guardian;
 - o Use partial deprivation instead of full deprivation in order to pay more attention to each individual case; evaluate capabilities of each individual person and limit legal capacity only in those areas in which incapacity is established without a doubt and always as a last resort;
 - o Provide detailed reasoning of the grounds for depriving someone of legal capacity;
 - o Use statutory authority to initiate ex officio proceedings for reinstating legal capacity, and establish a reporting system for all people who have been deprived of legal capacity so that court decisions are periodically reviewed;
 - o Act on requests for the reinstatement of legal capacity which are lodged by the persons themselves and/or the person's guardian;
 - o Critically examine the reports and opinions of court medical experts.

Living Independently and Inclusion in the Community

- Develop a more decisive policy in the field of de-institutionalisation, with forecasting of specific deadlines, steps and funding as envisaged for the transformation and eventual closure of residential units. Policy must be in conformity with the CRPD standards, which clearly confirm the right of each person to live in the community;
- Designate a specialized unit (preferably within the existent facilities) for coordinating all projects by various funding origins that are involved in developing and improving community services,
 - o The specialized unit should also be responsible for transferring best practices from countries with a well developed network of community services;
- Ensure that all parents, particularly those in smaller towns and rural areas, are familiar with community services, and that they have access to additional information on how they can influence the creation of such services in their communities;
- Strengthen and spread supported-living services through the use of beneficiaries' own housing units and by establishing support services;

- Work to transform day-care centres into resource centres for supporting parents and families, with the aim of including children in the education system or finding opportunities for adult employment;
- Work on professionalism / build skills among all service providers, particularly those in mainstream services, and ensure that professionals follow current reforms and changes in attitudes;
- Make all community services individually tailored, responsive and accessible to people with disabilities.

Education

- Apply sanctions in cases of gross violation of the right to education, such as when preschools or schools refuse to enrol a disabled child directly (or indirectly by imposing certain conditions: finding an assistant, presence of a parent, etc.);
- Ensure that all teaching and professional staff receive practical training on implementing the law and relevant rulebooks, in particular the rulebooks on IEPs and grading;
- Develop rules for realizing one's right to a teaching assistant, the criteria for realizing this right, and the manner of planning, hiring and financing this service;
- Promote positive examples of inclusion by highlighting different ways of overcoming specific challenges to inclusion;
- Develop and distribute practical guidelines for parents regarding their role in their child's education;
- Ensure that all schools involve parents in the processes related to planning their disabled child's education, in particular that parents receive a copy of all documents that are developed for their child;
- Enable school teaching staff to conduct study visits to model schools and to engage in the informal exchange of experience;
- Intensively inform schools, staff and parents about the existence and role of the Inclusive Education Support Network;
- Ensure that existing special schools and attached classes meet all legal requirement for providing adequate support to children, including obtaining an opinion from the intersectoral commission;
- Ensure that both regular and special schools initiate needs assessments for additional support before the intersectoral commission;
- Ensure that the schools' founding agencies (local, provincial and national governments) are aware of the importance of funding the support necessary for teaching local children with developmental difficulties living;
- Ensure that children with developmental difficulties residing in social care institutions receive education on an equal basis with others. With this in mind, develop a medium-term strategy for enrolling children from institutions into regular education at all levels, starting with preschool;
- Raise the awareness of all stakeholders regarding the role of the personal assistant and the difference between personal assistants and teaching assistants;
- Educate all stakeholders about the types and ways of using assistance technologies;
- Continually train the intersectoral commissions on the social model of disability and their role under the new law.

Work and Employment

- Enact the legislative changes necessary for ensuring that persons deprived of legal capacity will regain their right to work and employment;
- Ensure that persons who are deprived of legal capacity are not invisible for the National Employment Service and that they can register as unemployed and receive unemployment insurance and benefits, and can benefit from positive employment measures;
- Keep records that provide a full reflection of disabilities while ensuring that no disability-specific group of persons remains outside the scope of positive employment measures;
- Reform the work capacity assessment process; instead of evaluating a person's work capacity, the commission should be charged with evaluating the support and workplace adaptations required for a particular person to perform a particular job;
- Ensure that affirmative action measures intended to help disabled persons find employment

on the open labour market are directed equally at persons with varying kinds of disabilities (intellectual and other);

- Ensure greater transparency of the flow of the budgetary funds received from employer penalties paid for not hiring persons with disabilities;
- Raise awareness among employers, including Enterprises for the Professional Rehabilitation of Persons with Disabilities, regarding disabled persons' right to work, including persons with intellectual disabilities;
- Support creative initiatives developed by organizations involved in hiring disadvantaged persons with disabilities.

BIBLIOGRAPHY

Bibliography – The Convention on the Rights of Persons with Disabilities

Amicus Brief in the European Court of Human Rights, in the case of D.D. v. Lithuania, Application No 13469/06. The European Group of National Human Rights Institutions, April 2008.

Article 17 and inclusive education in the new UN Disability Convention: Briefing from the Centre for Studies on Inclusive Education. Centre for Studies on Inclusive Education (CSIE), 2004.

Bach, Michael. The right to legal capacity under the UN Convention on the rights of persons with disabilities: Key concepts and directions from law reform. Toronto: Institute for Research and Development on Inclusion and Society (IRIS), 2009.

Brown v. Board of Education, 347 U.S. 483 (1954).

Concluding observations of the Committee on the Rights of Persons with Disabilities on Spain's initial report; CRPD/C/ESP/CO/1, Sixth session. United Nations, General Assembly, Human Rights Council, 2011.

Concluding observations of the Committee on the Rights of Persons with Disabilities on Tunisia's initial report; CRPD/C/TUN/CO/1, Fifth session. United Nations, General Assembly, Human Rights Council, 2011.

Dhanda, Amita. "Legal capacity in the disability rights convention: Stranglehold of the past or lodestar for the future?" Syracuse Journal of International Law and Commerce 34, no. 2 (2007): 430.

Fourth session of the Conference of State Parties to the Convention on the Rights of Persons with Disabilities (New York, 7-9 Sep 2011): Background paper for Informal Session on Work and Employment, Note by the Secretariat, CRPD/CSP/2011/CRP.4. United Nations, Convention on the Rights of People with Disabilities, 2011.

General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant), 14 Dec 1990, E/1991/23. Office of the Higher Commissioner for Human Rights. UN Committee on Economic, Social and Cultural Rights (CESCR), 1990.

General Comment No. 5: Persons with Disabilities, 9 Dec 1994, E/1995/22. Office of the Higher Commissioner for Human Rights. UN Committee on Economic, Social and Cultural Rights (CESCR), 1994.

Nilsson, Anna. Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities. Commissioner for Human Rights: Strasbourg, 2012. <https://wcd.coe.int/ViewDoc.jsp?id=1908555>.

Parker, Camila. "An Overview of Article 19 of the UN Convention on the Rights of Persons with Disabilities in European Coalition for Community Living." Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities. European Coalition for Community Living, 2009.

Quinn, Gerard. Statement to the Oireachtas Joint Committee on Justice, Defense and Equality. Re: Hearing on the Mental Capacity Bill. Center for Disability Law and Policy. Ireland: NUI Galway, 2012. http://www.nuigalway.ie/cdlp/documents/cdlp_statement_to_oireachtas_justice_committee_on_mental_capacity_bill_final.pdf

Parker, Camila. *A Community for All: Implementing article 19, A Guide for Monitoring Progress on Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities*. Open Society Foundations, Open Society Mental Health Initiative, 2011.

Quinn, Gerard. *Concept Paper: Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD*. HPOD Conference: Harvard Law School, 2010.

Quinn, Gerard. "Disability and Human Rights: a New Field in the United Nations." Kruase, C. and Scheinin, M., (Eds), *International Protection of Human Rights*. Institute for Human Rights, Abo Academie University Finland, 2009.

Report of the Special Rapporteur on the Right to Education (Vernon Munoz), *The Right to Education of Persons with Disabilities*, UN doc. A/HRC/4/29, 19 February 2007. United Nations, Human Rights Council, 2007.

Right to Education: Scope and Implementation. General Comment No. 13: The Right to Education (Art. 13 of the Covenant on Economic, Social and Cultural Rights), E/C.12/1999/10. UN Committee on Economic, Social and Cultural Rights (CESCR), 2010.

Rosenthal, Eric, Jehn, Erin, and Galvan, Sofia. *Abandoned and Disappeared: Mexico's Segregation and Abuse of Children and Adults with Disabilities*. Disability Rights International and Comisión Mexicana de Defensa y Promoción de los Derechos Humanos, 2010.

Secretariat for the Convention on the Rights of Persons with Disabilities – UN-DESA and OHCHR – and Inter-Parliamentary Union. *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities - Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*. Geneva: United Nations, 2007.

The right of people with disabilities to live independently and be included in the community, CommDH/IssuePaper(2012)3. Strasbourg: Commissioner for Human Rights, 2012. <https://wcd.coe.int/ViewDoc.jsp?id=1917847#Top>.

U.N. Office of the High Commissioner of Human Rights. *Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, U.N. Doc. FILLIN "Symbol" * MERGEFORMAT A/HRC/10/48. United Nations, General Assembly, Human Rights Council, 2009.

Written submission pursuant to Rule 44(4) of the Rules of Court of the European Court of Human Rights, in the case of D.D. v. Lithuania, Application No 13469/06. Harvard Project on Disability, 2008.

X and Y v. Croatia , no 5193/09, ECtHR, Judgment 3.11.2011 [Section I]

Bibliography - Bosnia and Herzegovina

Bibliography – Bosnia and Herzegovina

Abdelbasit, Ana. *118 million steps to cooperation – allocations of the government sector for the non-government sector in B&H for 2008*. Sarajevo, 2009.

Adams, Lisa. *Right to live in a community: Exercise of this right for people with intellectual difficulties in Bosnia and Herzegovina, Montenegro, Serbia and Kosovo*. Disability Monitor Initiative, South East Europe, 2008.

Axelsson, Charlotte, Granier, Pascal, and Adams, Lisa. *Beyond deinstitutionalization: Unstable transition towards a system that provides opportunities in Southeast Europe*. Disability Monitor Initiative, South East Europe, 2004.

Ceranic, Dimitrije. Guardianship of persons deprived of legal capacity (legal regulations) in B&H. Faculty of Law, University of Istocno Sarajevo, 2007.

Cuk, Mira, Dobras, Zoran, Hopic, Danijel and Hopic, Jasmina. Evaluation of capacity of institutions and organizations which work in provision of aid to persons with disabilities. Collection of papers Research of situation in field of disability in B&H, 2008.

Dayton Peace Agreement, Annex 4, 14th December 1995, Constitution of Bosnia and Herzegovina.

Directorate for Education. Education Policy Committee. Educational Policies for Students at Risk and Students with Disabilities in South-Eastern Europe. Organization for Economic Co-operation and Development, 2007.

European Commission. Directorate-General for Employment, Social Affairs and Equal Opportunities. Report of the Ac Hoc Expert Group on the Transition from Institutional to Community-based Care. European Communities, 2008.

Federal Ministry of Labour and Social Policy. Standards on condition and service provision in institutions for social protection in FB&H. (Work in progress.)

Federal Ministry of Labour and Social Policy. Strategy for the Equalization of Opportunities for Persons with Disabilities in FB&H 2011-2015.

Federal Ministry of Labor and Social Welfare. Strategy of Improving the Social Status of Persons with Disabilities in the Republic of Srpska 2010 – 2015.

Ibralic, Fata. Characteristics of modern models of support aimed at improving the quality of life of persons with mental retardation.

Ibralic, Fata. Establishment of a Social Model in Rehabilitation of People with Mental Disabilities in Bosnia and Herzegovina, 2008.

Ibralic, Fata. Project: Establishment of a mixed model of social services for people with intellectual disabilities in the FB&H. Training material, 2011.

Ibralic, Fata and Smajic, Melika. People with intellectual disabilities - A contextual approach. Tuzla: Denfas, 2007.

Official Gazette of B&H, No. 76/08, Disability Policy.

Ibralic, Fata and Smajic, Melika. Self-advocacy of People with Mental Disability: We are persons in the first place, 2007.

Muhic, A., Amina. Halfway there – allocations of the government sector for the non-government sector in B&H for 2010. Sarajevo, 2011.

Official Gazette of B&H, No. 88/07, Framework Law on Pre-school Upbringing and Education.

Official Gazette of B&H, No. 18/03, Law on Primary and Secondary Education in B&H.

Official Gazette, Canton Sarajevo, No. 31/11, Law on changes and additions of the Law on Primary Upbringing and Education in Canton Sarajevo.

Official Gazette Canton Sarajevo, No. 23/10, Law on High School Education of Canton Sarajevo.

Official Gazette of the FB&H, No. 1/94, 13/97, 16/02, 22/02, 52/02, 60/02, 18/03, 63/03, Constitution of Federation of Bosnia and Herzegovina.

Official Gazette of the FB&H, No. 35/05, FB&H Family Law.

Official Gazette of the FB&H, No. 2/98, 39/04, 73/05, Law on Non-contentious Proceedings.

Official Gazette of the FB&H, No. 37/01, Law on Protection of Persons with Mental Disorders.

Official Gazette of the FB&H, No. 31/08, Law on Takeover of Rights and Obligations by the Founders of Social Protection Institutions in FB&H.

Official Gazette of the RB&H, No. 6/92, Decree Law on Institutions of FB&H.

Official Gazette of the RS, No. 6/92, 8/92, 15/92, 19/92, 21/92, 28/94, 8/96, 13/96, 15/96, 16/96, 21/96, 21/02, 30/02, 31/03, 98/03, Constitution of Republica Srpska.

Official Gazette of the RS, No. 36/09, Law on Non-contentious Proceedings.

Official Gazette of the RS, No. 98/04, Law on Professional Rehabilitation, Training and Employment of Persons with Disabilities in the Republic of Srpska.

Official Gazette of the SR of B&H, No 39/84, Law on Social Protection.

Official Gazette of the SR of B&H, 1988, Rulebook on general, technical and professional conditions for the establishment and operation of organizations of associated labor in the field of social protection.

Ombudsman. Special Report on the Situation of Human Rights in the Institutions for Accommodation of Mentally Disabled Persons, 2009.

Skočić, M., Sanja and Kiš – Glavaš, Lelija. Working and social competence of persons with intellectual difficulties. Employers' reasons for not employing such persons, 2010.

Topic, Boris. "Human rights of persons with mental disabilities: guardianship, and the limits of legal capacity." Puls demokratije, February 5, 2008. Accessed 28 November 2011. <http://arhiva.pulsdemokratije.net/index.php?&1=bs&id=713>.

UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: <http://www.unhcr.org/refworld/docid/45f973632.html>.

Report on the Work of the B&H Federation Employment Bureau for 2008.

Ward, H., Holmes, L. and Soper, J. Costs and Consequences of Placing Children in Care. London: Jessica Kingsley Publishers, 2008.

Zecevic, Amir. Legal regulation and status of institutions over which the rights and obligations have been taken by the founder by FB&H Parliament, 2001.

Action plan for reduction of obstacles for learning and participation of children with special educational needs in inclusive educational process. Association Life with Down Syndrome, 2012.

Strategic Directions of Education Development in Bosnia and Herzegovina with Implementation Plan, 2008–2015.

Support for inclusive education in curriculum. Association Life with Down Syndrome, 2011.

Support for inclusive education: teaching assistant. Association Life with Down Syndrome, 2011.

Bibliography - Kosovo

Constitution of the Republic of Kosovo.

European Training Foundation. Mapping Policies and Practises for the Preparation of Teachers for Inclusive Education in Contexts of Social and Cultural Diversity. Kosovo Country Report, 2010.

Kosova Education Center. Monitoring management of communal finances in education in five Kosovo municipalities. Accessed October 2011. <http://www.kec-ks.org/document%27s/MONITORIMI%20I%20MENAXHIMIT%20TE%20FINANCIVE%20KOMUNALE%20TE%20ARSIMIT.pdf>

Kosova Rehabilitation Centre for Torture Victims – KRCT. Human Rights Situation in Mental Health Institution 2011. Civil Rights Defenders – CRD.

Mental Disability Rights International. Kosovo Model: The Plan for Protection of Rights and Inclusion of People with Intellectual Disabilities. Mental Disability Rights International, 2007.

Ministry of Education, Science and Technology. Administrative Instruction, No.9/2007, Professional Assessment of Children with Special Needs.

Ministry of Education, Science and Technology. Brochure on Identifying, Assessing and Educating Children with Special Needs, 2007.

Ministry of Education, Science and Technology. Indicators and Statistical Data on Education, 2004-2007.

Ministry of Education, Science and Technology. Kosovo Education Strategic Plan 2011-2016.

Ministry of Education, Science and Technology. MEST Work Report for 2007.

Ministry of Education, Science and Technology. Statistics on Education in Kosovo, 2010-2011. Management Information System in Education.

Ministry of Education, Science and Technology. Statistics on Education 2010/2011.

Ministry of Education, Science and Technology. Strategic Plan for Organizing Inclusive Education of Children with Special Needs in Pre-university Education in Kosovo 2010 – 2015.

Ministry of Education, Science and Technology. Strategy for Development of Pre-University Education in Kosovo 2007-2017.

Ministry of Education, Science and Technology. Strategy Plan for Organizing All-inclusive Education of Children with Special Needs in Pre-university Education in Kosovo, 2010-2015.

Ministry of Education, Science and Technology. Transition from Special Schools to Resource Centre. Ministry of Education, Science and Technology/FSDEK-II, 2004.

Ministry of Health. Administrative Instruction Nr. 07/2009 for Professional Mental Health Services in Republic of Kosovo.

Ministry of Health. Mental Health Strategy in Kosovo 2008-2013.

Ministry of Health. Sectorial Health Strategy 2010-2014. Accessed November 2011. http://www.msh-ks.org/attachments/281_strategjia.pdf.

Ministry of Labour and Social Welfare. Activities of Ministry of Work and Social Welfare for 2010.

Ministry of Labour and Social Welfare. Administrative Instruction No. 03/2010 for Procedures to Apply to Have the Right on Skill Development, Retraining and Employment of People with Disabilities.

Ministry of Labour and Social Welfare. Administrative Instruction No. 06/2011, For Work and Placement of Residents, Persons with Mental Disabilities – Delay in Mental Development at the Special Institute in Shtime and in Homes with Community Based.

Ministry of Labour and Social Welfare. Administrative instruction No. 13/2010 for provision of services in community-home for persons with disabilities, mental-delay in mental development.

Ministry of Labour and Social Welfare. Administrative instruction 07/2011 for activities and requirements of placement of residents in house of elderly without family care homes and community based.

Ministry of Labour and Social Welfare. Disability Scheme in Kosovo. Accessed 23 February 2012. <http://www.scribd.com/doc/57108265/Regional-Meeting-on-Disability-Pension-in-Kosovo>.

Ministry of Labour and Social Welfare. Information on Workforce in Kosovo, November, 2011. Department of Work and Employment.

Ministry of Labour and Social Welfare. Regulation on Internal Organization of Work of the Special Institute in Shtime, No. 08/2006.

Ministry of Labour and Social Welfare. Regulation No. 08/2008 for Internal Organization of Work in the Special Institute in Shtime.

Ministry of Labour and Social Welfare. Role of Division in Institutional Care. Department for Social Welfare.

Ministry of Labour and Social Welfare. Work and Employment. Statistical Office of Kosovo, Kosovo Labor Survey.

Ministry of Labour and Social Welfare. Work and employment 2010, Yearly report 2010. Department of Work and Employment.

Office of the Prime Minister. Kosovo Agency of Statistics. Education Statistics, 2008/2009. Statistical Office of Kosovo.

Office of the Prime Minister. Kosovo Agency of Statistics. Education Statistics, 2009/2010. Statistical Office of Kosovo.

Office of the Prime Minister. Kosovo Agency of Statistics. Preliminary 2011 Census Results. Statistical Office of Kosovo.

Official Gazette of the Republic of Kosovo, No. 4/06, Family Law of Kosovo, No. 2004/32.

Official Gazette of the Republic of Kosovo, No. 37/08, Law for Material Support for Families of Children with Permanent Disabilities, No. 03/L-022.

Official Gazette of the Republic of Kosovo, No. 90/10, Law on Labour, Nr. 03-L-212.

Official Gazette of the Republic of Kosovo, No. 38/08, Law on Contested Procedure, No. 03/L-006.

Official Gazette of the Republic of Kosovo, No. 21/08, Law on Disability Pensions in Kosovo, No. 2003/23.

Official Gazette of the Republic of Kosovo, No. 45/09, Law on out Contentious Procedure, No. 03/L-007.

Official Gazette of the Republic of Kosovo, No. 31/08, Law on General Elections in the Republic of Kosovo, No. 03/L-073.

Official Gazette of the Republic of Kosovo, No. 15/07, Law on Occupational Safety, Health and the Working Environment, occupational safety, health and the working environment, No. 2003/19.

Official Gazette of the Republic of Kosovo, No. 14/11, Law on Pre-university Education, No. 04/L-032.

Official Gazette of the Republic of Kosovo, No. 8/06, Law on Primary and Secondary Education, No. 2002/2.

Official Gazette of the Republic of Kosovo, No. 13/07, Law on Rights and Responsibilities of Citizens in Health Care, No. 2004/38.

Official Gazette of the Republic of Kosovo, No. 12/07, Law on Social and Family Services, No. 02/L-17.

Official Gazette of the Republic of Kosovo, No. 47/09, Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities, Nr. 03/L-019.

Official Gazette of the Republic of Kosovo, No. 44/08, Provisional Criminal Code of Kosovo.

Official Gazette of the Republic of Kosovo, No. 14/07, The Anti-discrimination Law, No. 2004/3.

Ombudsperson Institution. About the legality of refraining people with mental disabilities in Special Institute in Shtime. Ombudsperson Institution, 2005.

Ombudsperson Institution. Ombudsperson's yearly report 2010.

Organization for Security and Cooperation in Europe. Adjudication of family law cases in Kosovo: Case management issues. OSCE Mission in Kosovo, 2011.

Prime Minister's Office. Broad Survey of Persons with Disabilities in Kosovo. UNDP/Prime Minister/Office of Good Governance, 2011.

Prime Minister's Office. First report on implementation of National Activity Plan for People with Disabilities in Kosovo 2009-2011. Office for Good Governance.

Prime Minister's Office. Regulation of Rules and Procedures of the Government of Kosovo, No. 09/2011. Prishtine, Kosovo.

Prime Minister's Office. Strategy and Action Plan on Human Rights of the Republic of Kosovo 2009 – 2011. Office for Good Governance.

United Nations Children's Fund. Justice Denied, The State of Education of Children with Special Needs in Post-Conflict Kosovo. UNICEF Kosovo/Engjujt, Kosovo Center for Advancement of Children, 2009.

United Nations Interim Administration Mission in Kosovo. All inclusive framework on the disability policies in Kosovo. UNMIK's Task force on disability issue, 2001.

United Nations Development Program. Kosovo Human Development Report 2010.

United Nations Interim Administration Mission in Kosovo. UNMIK's Regulation No. 2003/26.

United Nations Kosovo Team. Initial Observations on Gaps in Health Care Services in Kosovo.

Bibliography - Serbia

Beker, Kosana. Pravo da donesem odluku. Belgrade, Inicijativa za Inkluziju VelikiMali, 2010 <http://www.velikimali.org/doc/Publikacija.pdf>.

Buhrer Tavanier, Yana. 2009. Dumping Grounds for People. Accessed 6 January 2012. <http://dumpinggroundsforpeople.wordpress.com/read-the-investigation/full-length-investigation/>.

Government of the Republic of Serbia. First National Report on Social Inclusion and Poverty Reduction in the Republic of Serbia 2008-2010. Belgrade, 2011. <http://www.inkluzija.gov.rs/wp-content/uploads/2010/03/First-National-Report-on-Social-Inclusion-and-Poverty-Reduction.pdf>.

Helsinki Committee for Human Rights in Serbia. People on the Margins (Part 4): Social care institutions catering for children and adults with psycho-social disabilities and persons with mental disorders, 2009. Accessed December 2011. <http://www.helsinki.org.rs/doc/People%20On%20The%20Margins%20-%204.pdf>.

LifeLine website: Press Clipping: "Expression of Gratitude of the Ministry for Social Policy to HRH Crown Princess Katherine Foundation," Vreme, March 20, 2003. Accessed 6 January 2012. http://www.royalfamily.org/press/press-det/stampa-zahvalnica_yu.htm.

Loncar, Goran; Mihok, Zoltan; Grujić, Nikola; Sretenović, Aleksandra. Zapošljavanje osoba sa invaliditetom u Republici Srbiji, Centar za orijentaciju društva, Belgrade, 2011.

Mental Disability Rights International. Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities, 2007. <http://www.disabilityrightsintl.org/wordpress/wp-content/uploads/Serbia-rep-english.pdf>.

Ministry of Education and Science. Directions for further development of institutions for education of students with developmental difficulties and disabilities, working group draft. Belgrade, 2011.

Ministry of Human and Minority Rights, State Governance and Local Self-governance. Draft Initial Report on Implementation of the Convention on the Rights of Persons with Disabilities in Republic of Serbia, 2011.

Human Rights Watch. World Report 2011, Events of 2011. <http://www.hrw.org/world-report-2011>.

Ministry of Labor and Social Welfare. Report on Work of Centers for Social Work for the Year 2010. Belgrade, 2011. <http://www.zavodsz.gov.rs/PDF/izvestavanje/IZVESTAJ%20CSR%202010%20-%20FINAL.pdf>.

Ministry of Labor and Social Welfare. Report on Work of Institutions of Social Protection for Placement of Persons with Disabilities. Belgrade, 2011. <http://www.zavodsz.gov.rs/PDF/naslovna/god-izvestavanja/OSI.pdf>.

Ministry of Labor and Social Welfare. Izveštaj Ministarstva rada i socijalne politike o stanju u ustanovama za smeštaj dece, odraslih i starih sa posebnim potrebama, 2007. Accessed 6 January 2012. <http://www.minrzs.gov.rs/cms/yu/propisi/briga-o-porodici-i-socijalna-zastita>.

Official Gazette of the Republic of Serbia, No. 98/2010, Decision on the Network of Institutions of Social Care for Residential Placement of Users.

Official Gazette of the Republic of Serbia, No. 98/2006, Constitution of the Republic of Serbia.

Official Gazette of the Republic of Serbia, No. 18/2005 and 72/2011, Family Law.

Official Gazette of the Republic of Serbia, No. 42/2009, International Contracts.

Official Gazette of the Republic of Serbia No. 24/05, 61/05 and 54/2009, Labor Law.

Official Gazette of the Republic of Serbia, No. 51/2009 and 99/2011, Law on Associations of Citizens.

Official Gazette of the Republic of Serbia, No. 72/2009 and 52/2011, Law on the Basics of Education.

Official Gazette of the Republic of Serbia, No. 36/2009 and 88/2010, Law on Employment and Insurance in the Case of Unemployment.

Official Gazette of the Republic of Serbia, No. 18/2010, Law on Pre-school Education.

Official Gazette of Republic of Serbia, No. 33/2006, Law on Preventing Discrimination Against Persons with Disabilities.

Official Gazette of the Republic of Serbia, No.36/2010, Law on Prevention of Abuse at Workplace.

Official Gazette of the Republic of Serbia, No. 36/2009, Law on Professional Rehabilitation and Employment of Persons with Disabilities.

Official Gazette of Republic of Serbia, No. 22/2009, Law on Prohibition of Discrimination.

Official Gazette of the Republic of Serbia, No.24/2011, Law of Social Protection.

Official Gazette of the Republic of Serbia, No. 63/2010, Rulebook on Additional Education, Health and Social Support to Child and Student.

Official Gazette of the Republic of Serbia, No. 88/93 and 53/2005, Rulebook on closer conditions for start of work and operation and norms and standards for operation of institutions for social care for placement of adult persons with disruptions in mental development, mental illness and invalid persons.

Official Gazette of the Republic of Serbia, No. 74/2011, Rulebook on closer instructions for establishing a right to individual educational plan, its implementation and evaluation.

Official Gazette of the Republic of Serbia No. 15/92, 100/93, 12/94/ 51/97, 70/2003, 99/2004, 100/2004, 25/2005, 77/2005, 60/2006 and 8/2011, Rulebook on criteria and measures for establishing prices of services in the field of social protection which are financed by the Republic.

Official Gazette of the Republic of Serbia, Nr. 74/11, Rulebook on Grading Students in Primary Education.

Official Gazette of the Republic of Serbia No. 33/10 and 48/10, Rulebook on manner of monitoring completion of obligation to employ persons with disabilities and manner of proving that obligation.

Official Gazette of the Republic of Serbia, No. 15/2010, Rulebook on more detailed content of data and keeping registry in the area of employment.

Official Gazette of the Republic of Serbia, No. 108/2005, 71/05, Strategy for Development of Social Protection.

Official Gazette of the Republic of Serbia, No.36/10, Rulebook on more detailed way, costs and criteria for assessment of work capacity and possibilities of employment or preserving employment of persons with disabilities.

Official Gazette of the Republic of Serbia, Nr. 16/05, 2/06, and 7/2011, Zakon o ratifikaciji Opcionog protokola uz Konvenciju protiv torture i drugih surovih, neljudskih ili ponižavajućih kazni i postupaka.

Official Gazette of the Socialist Federal Republic of Yugoslavia, No. 29/78, 39/85, 45/89 - decision of the Constitutional Court of Yugoslavia and 57/89; Official Gazette of Socialist Republic of Yugoslavia, No. 31/93 and Official Gazette of Serbia and Montenegro, No. 1/2003 – Constitutional Charter, Law on Obligation Relations.

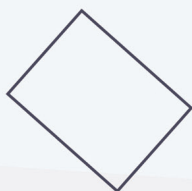
Official Gazette of the Socialist Republic of Serbia, No. 33/97, 31/2001 and Official Gazette of the Republic of Serbia, No. 30/2010, General Administrative Law.

Official Gazette of the Socialist Republic of Serbia, No. 25/82 and 48/1988 and Official Gazette of the Republic of Serbia, No. 46/95 and 18/2005, Non-contentious Proceedings Act.

Ombudsman. Report on control of conditions of stay and respect of right of users, with a specific focus on socio-psychological and health protection in Special Institution for Children and Young Persons Dr. Nikola Šumenković in Starnica, 2009. Accessed 6 January 2012. http://www.ombudsman.rs/index.php/lang-sr_YU/izvestaji/posebnii-izvestaji/501--q-q-.

Ombudsman. Special Report of the Ombudsman on Inspections Conducted in Social Care Homes for Elderly in 2010. Belgrade, 2011. <http://www.ombudsman.rs/index.php/lang-sr/izvestaji/posebnii-izvestaji/2108--2010>.

Public conference MDRI-S and Belgrade center for human rights: Legal capacity as a human right in Serbia, Belgrade, 28 October 2011.



BOSNIA AND HERZEGOVINA, KOSOVO, SERBIA



This publication has been produced with the financial assistance of the European Union. The contents of this document are the sole responsibility of People in Need and can under no circumstances be regarded as reflecting the position of the European Union



The project is co-financed by the Czech Development Agency and the Ministry Foreign Affairs of the Czech Republic within the framework of the Czech Development Cooperation program

