

# Children with Disabilities in Bosnia and Herzegovina: I Don't Think I Am Different



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World Vision 

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# Impressum

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# Review selection

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*World Vision's research, which was conducted during 2015 and 2016, is primarily dedicated to the rights and status of children with disabilities and their families in BiH society, which gives it a special value. The research results have shown, inter alia, that there is no comprehensive and harmonized approach in creating systemic solutions which would ensure that children with disabilities and their families receive appropriate forms of support, but also become the actors of the processes that most directly concern them.*

*The greatest value of this research is reflected in the fact that its key findings are based on the testimonies of children with disabilities, their parents, their family members, neighbors and friends, and that on the basis of these statements and the statements of other participants in the research, and thanks to the analysis of the institutional and legal framework governing the rights of children with disabilities in Bosnia and Herzegovina, recommendations were created for action by the key actors, in order to create the preconditions for full respect of the rights and inclusion of children with disabilities in all segments of society on an equal footing with their peers.*

*The recommendations contained in the study correlate with the recommendations from the Alternative Report on the implementation of the Convention on the Rights of Persons with Disabilities in BiH which a group of 65 disabled people's organizations submitted to the Committee on the Rights of Persons with Disabilities of the United Nations. We believe that the recommendations that form part of this study should serve as a basis for launching various initiatives for changes in the legislative framework, as well as other changes in society that will ensure the full enjoyment of the rights of children with disabilities and their full participation in society, as well as the necessary forms of support to parents and families of children with disabilities.*

*We hope that, because of its value, this study will greatly contribute to the changes that will bring about a more dignified status of children with disabilities and their families in BiH society, and will help their organizations obtain the appropriate forms of support and ensure their status as the main promoters, protectors and advocates of the rights and dignity of persons with disabilities, but also as partners to any interested parties in addressing the issues of concern to children with disabilities and their families, and persons with disabilities in general.*

Suvad Zahirović, Information Center for Persons with Disabilities Lotos

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# Preface

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It is with great pleasure that we present the results of our research project, exploring the needs and priorities of children with disabilities and their families in Bosnia and Herzegovina. This report provides an important insight into the status, needs and daily challenges faced by children with disabilities and their families across the country.

For the purpose of this report, twenty children and their families opened their hearts and homes to give us a glimpse into their everyday life. Their stories are unique, revealing their struggles, challenges, hopes and dreams for the future. Children living with disabilities in Bosnia and Herzegovina often experience social isolation and discrimination from broader society. They are rarely valued for their full contribution, and for the different qualities that they bring to their schools and communities, and the stigma attached to living with a disability creates even more isolation and loneliness.

Even though the overall situation of children with disabilities in Bosnia and Herzegovina has seen some improvement in the last 20 years, there is much improvement to be made to achieve the minimum standards defined in the international legal framework such as those in the UN Convention on the Rights of Persons with Disabilities, as well as in the BiH legislation

For example, families caring for children living with a disability deserve and need support and services. As Edo, father of a child with a disability stated 'You will get the diagnosis on an A4 paper from the government and they are done with you. For everything else you have to fight on your own'.

I would like to use this opportunity to call on all members of society to work together and, with persistence and determination, ensure that all children, regardless of their abilities, are protected, cared for and given the opportunity to enjoy life in all its fullness.

In solidarity,

Sarah Bearup  
World Vision Bosnia and Herzegovina  
National director



# 1. Executive Summary

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## 1.1. Summary of research purpose and scope

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The following research was conducted in order to get an insight into the lives of children with disabilities and their families in Bosnia and Herzegovina (BiH). Despite the considerable attention given to issues faced by children and to issues faced by persons with disabilities, specific findings on the everyday life of children with disabilities is rare. The scope of the research includes all types of disabilities children live with, and all areas of BiH (including both, Federation of BiH - FBiH and Republika Srpska - RS, as well as all FBiH cantons). The research was conducted during 2016 with the participation of two lead researchers, fourteen (14) field researchers, one desk researcher and an author. A qualitative methodology was employed, with in-depth interviews conducted with twenty (20) children with disabilities, their families, friends, neighbors and care givers or service providers living in twenty locations of BiH. A total of fifteen (15) focus groups took place in another five locations in BiH. The research also used an advocacy/participative approach and all conclusions are followed by concrete recommendations addressing specific groups of society.

## 1.2. Summary of findings and recommendations

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The overall situation of children with disabilities in BiH has seen some improvement in the last 20 years, but it is still well beyond the standards prescribed by the international legal framework such as the UN Convention on the Rights of Persons with Disabilities (CRPD), as well as the BiH legislation and Disability Policy. The evidence compiled in earlier studies of the poor quality of life of children with disabilities was confirmed by the findings of this research, too. The issues identified as obstacles to a dignified life of equal opportunities begin with the diagnosis process, lack of adequate health services and sensitive health professionals, poor inclusive education or limited and underdeveloped special schools, medical approach towards children with disabilities that supports existing socio-medical institutionalization, segregation and exclusion.

The success of inclusive education in BiH currently rests solely on the willingness and interest of individual professional staff (teachers, speech therapists, defectologists<sup>1</sup>, etc.) and parents of children with disabilities. It has also contributed to the existing conclusions on the lack of capacity of BiH governments to implement the existing legal and policy frameworks that would enable the children with disabilities to enjoy their right to education. Despite many good experiences and best practices that can and should be replicated, each of the stories told by the children with disabilities, their parents, education staff, neighbors and classmates always had at least one example of an obstacle they face in accessing their school on a daily basis. There were also stories of children who do not have any access to education.

The principal challenge in implementing the CRPD standards for service provision for BiH governments at all levels is the poor allocation of financial resources. The scope of these rights, in particular the social (financial) support, as well as support to other services, is lacking and needs to be improved in BiH in all areas discussed: social protection services, health services, assistive technologies, specialized services, and continuous education, training and sensitization of staff working with children with disabilities.

Parents are their children's first teachers, however in situations where mandated institutions do not provide the necessary services, the parents have been entirely encumbered with the role of local authorities. The support for parents and families of children with disabilities is rare, depends on the good will of neighbors, non-governmental organizations (NGO) and charities.

Health services in BiH do not include services that are accessible for persons with disabilities, and in particular for children with disabilities. Children with disabilities who spend a good part of their childhood getting treatment in hospitals have experienced together with their parents the lack of early warning systems, expertise of staff or access to expertise in BiH, accessible spaces and information, and lack of adequate equipment, medication, and assistive aids to suit their needs.

Parents of children with disabilities, as well as entire families that have children with disabilities, face the risk of falling into poverty due to increased expenditures for the care and other services of their child with disabilities. All of the interviews mentioned the hardship of the lack of finances for everyday survival, and in particular for specific assistive aids that are thus, due to lack of government funding and families already impoverished with the disability, often completely out of the reach of children with disabilities.

Ableism is a socially created phenomenon that needs to be addressed by those professionals and institutions that are at the forefront of contact with persons with

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<sup>1</sup> The meaning closest to 'defectologist' would be rehabilitator or special education teacher. The term was inherited from classification of professions in former Yugoslavia, and is closely associated with the eastern European/Russian school of thought at the time, which viewed persons with disabilities as 'defective/damaged'.

disabilities - the health and social protection, and education sectors. They have a significant role in influencing the general population (and thus are responsible for creating societies sensitive to disability issues or those that are prejudiced), but most importantly influencing the key supporters of children with disabilities - their parents and family.

Prejudices about disability in our society - that has become disabled because it does not create an environment that is accessible for all its citizens - have resulted in children with disabilities usually being left in isolation, without possibilities for socialization and enjoyment of basic rights. The lack of awareness is present among service providers in health and education institutions - save some positive, but rare examples, as well as within local communities, in everyday life. Children with disabilities do not want to be different from other children in BiH, but the environment and conditions they live in force them to feel that way.

Table 1. Thematic Recommendations

		Objective	Necessary Actions	Actors
Poverty alleviation	Employment opportunities	Consistent employment for parents of children with disabilities	<ul style="list-style-type: none"> <li>- NGOs provide a small “volunteer” stipend for the parents’ work at the centers</li> <li>- Employment Agencies develop employment programs targeting parents of children with disabilities</li> </ul>	Employment Agencies NGOs Parents
	Vocational training	Young adults with disabilities included in existing vocational training programs	<ul style="list-style-type: none"> <li>- Programs already providing vocational training to persons with disabilities develop programs for youth with disabilities</li> <li>- Job market informs training choices</li> </ul>	Ministries with mandate for employment, entrepreneurship NGOs Families Youth with disabilities
		Activity Centers for young adults with disabilities	<ul style="list-style-type: none"> <li>- Activity centers where young adults with disabilities and their parents may earn an income through collective, on-site income generating activities</li> </ul>	Government <sup>2</sup> NGOs Parents Youth with disabilities
		Employment opportunities for young adults with disabilities	<ul style="list-style-type: none"> <li>- Parents and young adults with disabilities advocate for businesses to hire young adults with disabilities</li> <li>- Government encourages hiring of young adults with disabilities through favorable taxes</li> </ul>	Government Local businesses Parents Young adults with disabilities
		Employment support programs for young adults with disabilities	<ul style="list-style-type: none"> <li>- Support program for employment of youth to include work assistants, mentoring programs for various employment sectors, in particular in public employment</li> <li>- Procedures for giving priority during employment for young adults with disabilities defined and promoted</li> </ul>	Government
Inclusion in society	Awareness of CWDs	Need to integrate children with disabilities and their families into existing systems of service provision	<ul style="list-style-type: none"> <li>- Working group composed of relevant ministry staff and relevant NGOs explore methods of incorporating CWDs</li> <li>- Current CBR programming adapted to unique CWD needs</li> <li>- Relevant government ministries take a lead role in project planning, implementation, follow-up</li> </ul>	Ministries of social protection Ministries of health protection Ministries of education NGOs

<sup>2</sup> All levels of government in BiH

		Objective	Necessary Actions	Actors
Inclusion in society	Awareness of CWDs	Communities support children with disabilities and their families	<ul style="list-style-type: none"> <li>- Relevant government ministries in cooperation with NGOs conduct awareness raising workshops and events for local authorities</li> <li>- Teach local authorities about the needs and rights of children with disabilities so that they can relay information to community members</li> </ul>	Ministries of social protection Ministries of health protection Ministries of education NGOs Local authorities Community members
	Advocacy	Children with disabilities exercise their right to education	<ul style="list-style-type: none"> <li>- Increase in formal and non-formal educational opportunities for children with disabilities</li> <li>- Ministries and NGOs form mutually beneficial partnerships that positively impact students and staff</li> </ul>	Ministries of education NGOs Local authorities Teachers
		The right to dignified employment of young persons with disabilities recognized	<ul style="list-style-type: none"> <li>- Parents, with support from government, advocate for the right to employment of young persons with disabilities within the private sector</li> <li>- Businesses conducive to employing young persons with disabilities are identified</li> <li>- Tax benefits encourage private businesses to employ young persons with disabilities</li> </ul>	Businesses Persons with disabilities Young persons with disabilities
	Policy Development	National policy on CWDs	<ul style="list-style-type: none"> <li>- Ministries and NGOs develop programs for CWDs that involve families, community members and government</li> </ul>	Ministries of social protection, of education, of health protection, of employment NGOs Families Community members CWDs
	Education	Inclusive schools implemented throughout education system	<ul style="list-style-type: none"> <li>- Governments provide adequate funding for schools, training institutes, and universities</li> <li>- Education assistants provided and trained by government institutions</li> <li>- Plans developed to overcome architectural barriers, information access barriers, provision of adequate teaching materials for children with disabilities at all levels of education - monitoring and implementation of plans ensured with adequate funding</li> <li>- Parents trained at the earliest possible time in order to ensure adequate support for the inclusive education of their children with disabilities</li> <li>- Technical means provided for children with disabilities to reflect their individual education needs</li> </ul>	Ministries of education Institutes of education Schools Universities Personal assistants Parents

		Objective	Necessary Actions	Actors
Inclusion in society	Education	Staff in education system sensitized and supported	<ul style="list-style-type: none"> <li>- Curricula for training all education and support staff developed with support of expert persons with disabilities</li> <li>- Training for all educational staff</li> <li>- Adapted curricula and teaching instruments and textbooks</li> <li>- Quick and user-friendly development of individual programs</li> <li>- Multidisciplinary teams established for individual assessment needs for inclusive education for children with disabilities</li> </ul>	Ministries and Institutes of education Schools Universities Teachers Pedagogues Defectologists Therapists
		Parent education developed and provided	<ul style="list-style-type: none"> <li>- Programs introduced that provide parent education in order to reduce negative child-parent interactions and subsequent behavioral problems</li> </ul>	Institutes of education Schools Universities Teachers Pedagogues Parents
	Services	Services for children with disabilities developed for all disability situations	<ul style="list-style-type: none"> <li>- Government provides adequate financial resources</li> <li>- All services for children with disabilities, whenever possible, provided as part of mainstream services for non-disabled children</li> <li>- Children, young adults and families of children with disabilities included in the development of service planning</li> <li>- Disabled persons' organizations enabled to participate in service provision</li> <li>- Multidisciplinary working groups periodically implement evaluation of existing services and take into account possibility of introducing new ones</li> </ul>	Ministries for social and health protection Centers for Social Work Health Centers NGOs Children and young adults with disabilities Parents and families
	Health	Cross-sectoral early identification of disability programs for children developed	<ul style="list-style-type: none"> <li>- Cross-sectoral working groups established and cooperation and reporting mechanisms developed</li> <li>- Periodic reports on patient satisfaction and quality of health services provided to children with disabilities</li> </ul>	Ministries of health, of social protection, of education, Centers for social work, Health centers, Schools, Hospitals
		Diagnosis processes developed as a "one-stop-shop"	<ul style="list-style-type: none"> <li>- Diagnosis process envisaged to take place in one location</li> <li>- Diagnosis processes take into account the need to support the families of children with disabilities and their emotional and psychological challenges during the diagnosis</li> </ul>	Institutes for medical assessment of disabilities Ministries of health, of social protection, of education, Centers for social work, Health centers, Schools, Hospitals

		Objective	Necessary Actions	Actors
Inclusion in society	Health	Revision of capacities of medical and paramedical staff	<ul style="list-style-type: none"> <li>- General staff recognizes disabilities</li> <li>- Specialized staff further specializes in disabilities</li> <li>- All staff aware of anti-discrimination principles and sensitive to children with disabilities</li> </ul>	Ministries of health Hospitals Health centers Doctors Nurses Medical technicians
		Accessible and children with disabilities-friendly hospitals	<ul style="list-style-type: none"> <li>- Revision of necessary adaptation of existing medical facilities in order to be accessible for all children with disabilities</li> <li>- Provision of adequate physical and informational accessibility to children with disabilities</li> <li>- Creation of child and disability-friendly environments</li> <li>- Necessary and adequate equipment and medication for children with disabilities procured</li> </ul>	Ministries of health Hospitals Health centers Doctors Nurses Medical technicians
		Assistive technologies available for all children with disabilities	<ul style="list-style-type: none"> <li>- Institutions in charge of assessing the need for assistive devices and purchasing them in order to ensure those are always suited to the specific needs of a child with disabilities</li> <li>- Assistive technologies include those that are required for different skills and tasks in education, organization of activities and everyday life, that will increase the independence of children with disabilities</li> </ul>	Ministries of health



# 2. Introduction

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## 2.1. Purpose of research

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Children with disabilities (CWDs) are one of the most marginalized and excluded groups in BiH. They are often likely to be among the most vulnerable and poorest members of the population, are less likely to attend school, and have access to medical services. Their disabilities also place them at a higher risk of physical abuse. Statistics and information regarding CWDs living in BiH are limited which complicates planning and service delivery for government, as well as organizations active in supporting and protecting children in their programs.

The main purpose of this research is to reflect the current lack of data and information about the lives of children with disabilities and to provide a deeper understanding of a day in the life of children with disabilities and their families in BiH. The voice of children with disabilities and experiences of their families, their friends as well as persons who support them, are usually not heard and this research aims to put them in the spotlight. This research is in particular addressing the government institutions at all levels of BiH governance, as it includes a plethora of data and information that can be used for the future development of policies and legislation that will support and protect the children with disabilities and their families.

The research was conducted in two phases, the first including semi-structured interviews with children with disabilities and their accompanying research participants, and the second phase including focus groups with local authorities' representatives of public institutions providing support to children with disabilities.

This research targets a varied audience, but it is primarily addressing the responsible government ministries, public institutions and professionals, as well as the non-governmental sector engaged in providing various services for children with disabilities, including those that should primarily be provided by the state. It also aims to bring the issues related to the lives of children with disabilities and their significant others closer to the general public whose better understanding and appreciation of the problem will contribute to reduction of stigma and prejudice and with that enhance quality of life of this vulnerable group.

## 2.2. Scope and limitations of research

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The research was designed as to set out to identify the needs and problems faced by children with disabilities and their families throughout BiH. It was foreseen as qualitative research and thus not representative of all of the experiences of children with disabilities. The focus was to provide an in-depth understanding of the obstacles and problems faced by research participants, ways of how they mitigate them, lessons learned from their experiences, as well as best practices that could be replicated. This approach has limited the scope of the research only to those life experiences shared by the research participants, that do not necessarily include all of the problems children with disabilities face in BiH. However, given that many of the research findings corroborated existing studies and analyses on disability issues, these limitations did not reduce the credibility of the findings of this research.

The research team made every effort to include a balance of children with different areas of disability, but this was not entirely possible, as some of the initially identified children and/or their parents did not participate in the research and ended being replaced by children representing a disability area different than the originally intended one. Equally the information on the exact diagnosis proved to be wrong after the interview, thus placing the child into a different disability area. This has led to more research participant from one disability area, nevertheless all disability areas remained represented by at least two research participants thus maintaining its credibility. Given that the children and their families participating in this research were contacted through the local authorities and non-governmental organizations, the research did not have an opportunity to access children and families who are not included in any local services or programs.

Every possible avenue was taken in order to encourage and include children with disabilities themselves in the research. Whenever children with disabilities were interested and willing they were interviewed, when this was not possible, the number of other family members and support individuals closest to them (assistants, neighbors, peers and friends) were included in the interviews.

Despite these identified limitations, it is noteworthy that the recommendations based on the research findings once implemented will contribute to the improvement of the lives of all children with disabilities and their families in BiH.

# 3. Methodology and Methods

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## 3.1. Description of research methodological approaches

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The research methodology was conducted within a qualitative, bottom-up approach, that provided the research participants more freedom and flexibility in expressing their experiences and views. The research was driven by the research topic and purpose, to reflect a day in the life of families with children with disabilities and their relations within their community in BiH.

This research was also guided by an advocacy/participatory approach to research, in hope that the provided recommendations would initiate appropriate action on behalf of governmental and non-governmental organizations and thus bring about improved awareness and positive changes in the lives of the children with disabilities and their families as research participants. This approach is in particular used for research participants who are socially excluded, as socially excluded groups are rarely in a position of power within society. For this reason, some of the researchers were also members of the group they were studying, i.e. members of the disability movement of BiH.

In order to provide a sufficient qualitative in-depth analysis of the lives of children with disabilities and their families, the research participants did not only involve children and their parents, but also their teachers, personal assistants, other professionals, neighbors and friends.

## 3.2. Presentation of sampling method and purpose

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Prior to the finalization of the research instruments, the lead researchers consulted thirty-one (31) organizations and institutions offering support to children with

disabilities and their families throughout BiH. These consultations provided an input for the key topics for the research instruments.

The sampling was guided by two key principles: to include children with different kinds of disabilities, and to ensure the research participants come from different parts of BiH, covering as much of BiH towns and municipalities as possible, equally its urban, semi-urban and rural areas. In order to provide a manageable set of data for analysis, twenty (20) interviews were planned and conducted with research participants in twenty (20) different locations in BiH (to include both Republika Srpska and the Federation of BiH, as well as many cantons of FBiH as possible).<sup>3</sup> The aim was to roughly include a quarter of all research participants who would represent one of the four main different areas of disability: sight, hearing, mobility and intellectual/autism. The selection of research participants was organized in cooperation with the Centers for Social Work, Primary Schools, Rehabilitation Centers and Disabled Persons' Organizations, who contacted their clients/members and then provided the research team with the interested participants' contact details.

The twenty (20) children with disabilities who were research participants came from the following disability groups affecting:

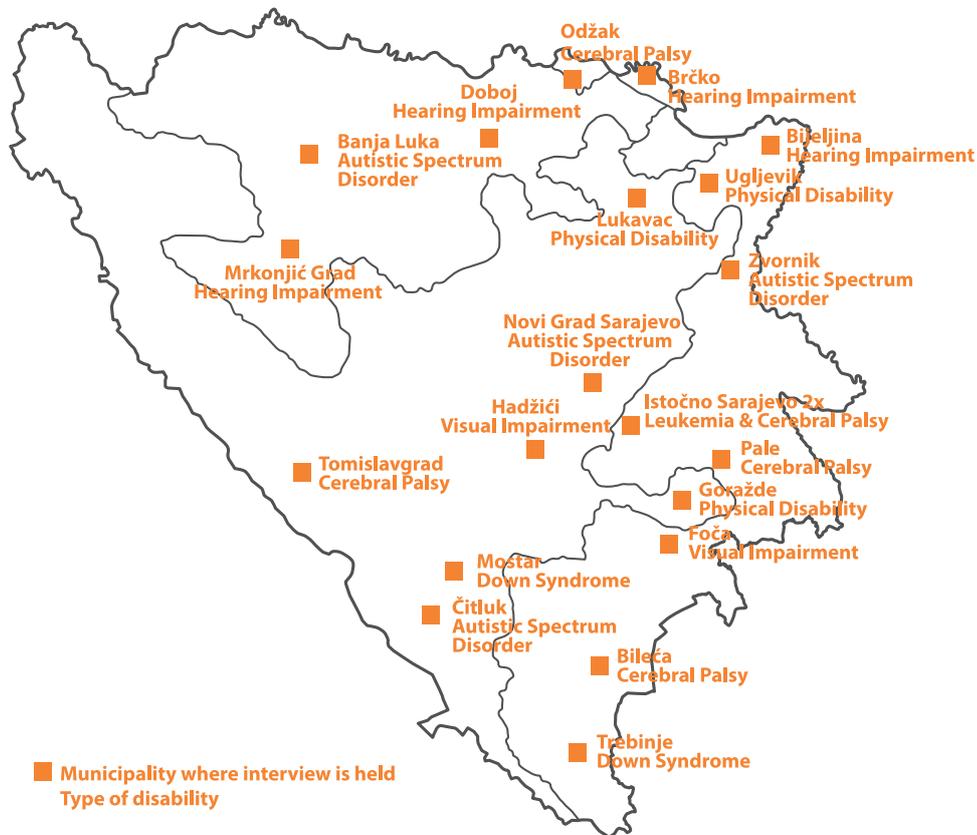
- sight (three)
- hearing (three)
- mobility (nine: six with cerebral palsy, one muscular dystrophy, two with other mobility disability)
- intellectual capacity/autism (five: two Down syndrome, three autism spectrum disorder)

The towns and municipalities included were: Banja Luka, Bijeljina, Bileća, Brčko, Čitluk, Doboј, Foča, Goražde, Hadžići, Istočno Sarajevo, Lukavac, Mostar, Mrkonjić Grad, Novi Grad Sarajevo, Odžak, Pale, Tomislavgrad, Trebinje, Ugljevik i Zvornik.

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<sup>3</sup> The research team initially included 25 interviews, out of which 5 were conducted with children with chronic or terminal illnesses, while only 20 interviews with children with disabilities *per se* were analysed in this report.

Figure 1. Map of research participants with geographical location and area of disability

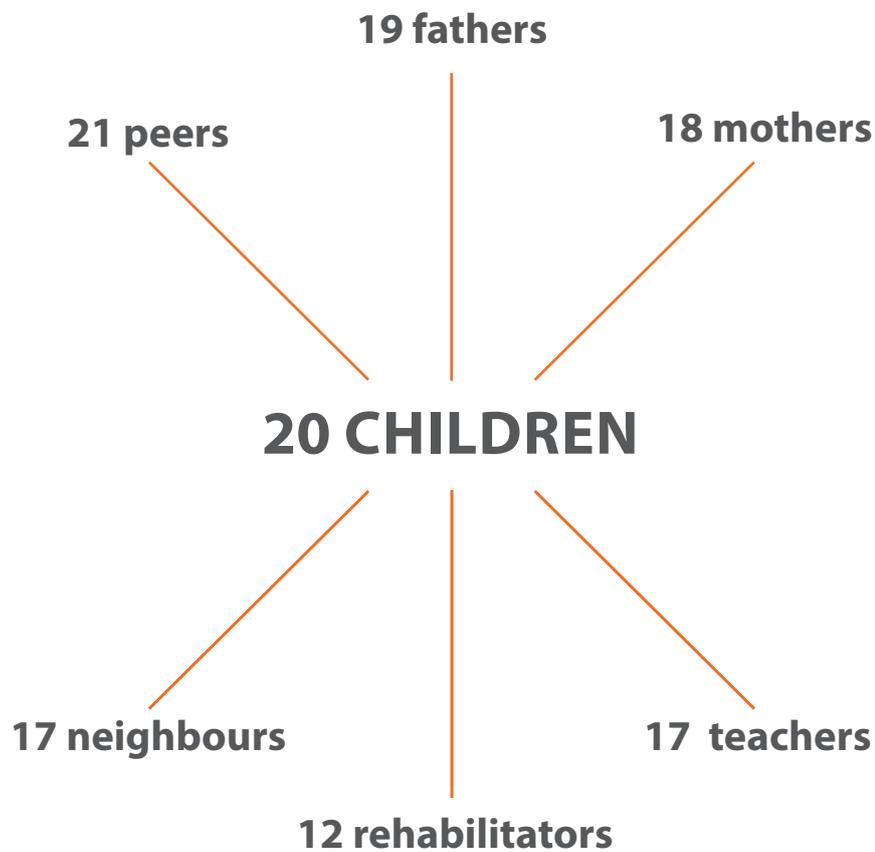


Approximately 52% of the children were girls and 48% were boys reflecting the distribution of population by sex in BiH.

Interviews were conducted with all children who had the possibility to participate, and if a child could not participate, interviews were conducted with their parents, neighbors, and significant others. The aim was to interview both parents, and a total of nineteen (19) interviews with fathers and eighteen (18) interviews with mothers were conducted. Teachers and/or other professionals working with children who were attending any kind of formal or informal education were included in the interviewing, too (17 teachers, 3 speech therapists, 3 defectologists, 1 psychologist, 2 personal assistants, 2 social workers and 1 pediatrician). Seventeen (17) interviews with neighbors living in the vicinity of the family with children with disability were included, as well as twenty-one (21) interviews with the children's friends.

The focus group sampling was directed by the locations of World Vision Area Program interventions as that would provide a better access to local authorities and increase their willingness and availability for participation in the research.

Figure 2. Number of interviews per relationship with the child



A total of fifteen (15) focus groups were organized, five each with: primary and secondary school age children; teachers; and field expert employees of health, social welfare, education and civil society organizations/institutions. The focus groups took place in Dobož, Lukavac, Olovo, Pale, and Petrovo and included participation of 47 field experts,<sup>4</sup> 49 teachers and rehabilitators from primary and secondary schools, and 82 children from primary and secondary schools.

<sup>4</sup> Participants of these focus groups were: paediatricians, psychologists, defectologists, social workers, pedagogues and NGO managers, coming from Health Centres, Schools, Centres for Social Work and NGOs recognized as organizations with experience in supporting children with disabilities.

### **3.3. Presentation of methods used in research and their purpose**

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The instruments used for this research included consultations, semi-structured interviews and focus groups.

The consultations with 31 disabled persons' organizations, rehabilitation centers and public institutions included key questions pertaining to the challenges faced by children with disabilities, services (not) available, their inclusion in society, strengths and weaknesses of existing disability movement networks, required revision of existing policies on disability, as well as the availability of research participants for interviews.

These consultations provided input in the development of the semi-structured interview questionnaire that reflected the main challenges children with disabilities and their families are faced with including: parents' experience of their children's disability, availability of professional experts for the specific disability, quality and access to services, social inclusion, inclusive education and deinstitutionalization, diagnostic procedures, other barriers to a dignified life and priorities for future.

The focus groups included the following research questions: quality, capacities of and access to services for children with disabilities, required revision of existing policies on disability, inclusive education, social inclusion, early intervention opportunities, and availability of professional experts for the specific disability.

### **3.4. Data collection, management, and analysis**

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The Wings of Hope team conducting the field research was directed by two lead researchers, who also participated with another fourteen (14) field researchers. All researchers participated in the data collection and preliminary analysis under the guidance of the two lead researchers. The research analysis was finalized by a World Vision author who joined the team in order to write up the report.

All field researchers attended a training on research guidelines and World Vision "Child Protection Policies" in order to ensure a uniform approach throughout the research process and ensure children's best interest and their human rights are respected.

All interviewees were informed that their participation in the research was anonymous. All interviewees were asked for the permission to audio record the interview and sign the consent forms. In the case when this was not possible, researchers took notes during the interviews. Audio interviews were not fully transcribed, and part of this material was used to develop a case study for each child including quotes from respondents and researchers' observation from interviews. Focus groups were conducted by five senior researchers in schools and local centers for rehabilitation of children with disabilities. Focus group interviews were not transcribed. At all times the confidentiality of the research material was strictly respected and maintained both at Wings of Hope and World Vision.

Twenty (20) Case Story Reports and fifteen (15) Focus Group Reports were developed based on content analysis. The report writing was built on the case story and focus group reports as the main source of data. The report chapters include a brief overview of status of persons with disabilities in BiH (chapter 4), an analysis of the findings that are divided into seven sub-chapters that reflect the patterns of topics on key issues for children with disabilities in BiH (chapter 5). Each of the sub-chapters starts out with a brief overview of the legal and policy framework relevant to theme discussed and the extent to which it is implemented (latter, if available), continues to present the findings on topic discussed including quotes from research participants and concludes on how the findings impact the lives of children with disabilities with recommendations. The remaining chapter includes conclusions and recommendations (chapter 6) that target key stakeholders who are obliged to address issues faced by children with disabilities and their families.

# 4. Overview of Status of Children with Disabilities in BiH<sup>5</sup>

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The legal system in BiH is organized in a such way that all of the questions regarding human rights of persons with disabilities are resolved on the entity and/or cantonal levels.

Acquired policies and regulations on the entities level have still not adopted a unique definition of disability and ministries with a mandate in this field are not taking any new steps in that regard. In many regulations and legislations terms in use are prohibited by the CRPD and the inherent approach is more in the line of medical model which takes into consideration only physical disorder of people with disabilities. In some legislation the prohibition of discrimination on the basis of disability is recognized as in the laws from the fields of labor, education and health care. Even in these laws in which prohibition of discrimination based on disability is directly stated, there are no effective measures for preventing such discrimination from happening.

The 2014 Alternative Report on the Implementation of the UN CRPD for BiH identifies some key issues that affect persons with disabilities, as well as children with disabilities in BiH: there is no reliable data on persons with disabilities, including their capacities and needs; the education system is inaccessible to most persons with disabilities; there is a lack of medical protection and/or poor health services; persons with disabilities face multiple discrimination based on gender, age and geographical location; and there is a lack of sensitivity and awareness on disability issues, even by those who provide services to persons with disabilities.

There is no official data about the number of people with disabilities living in BiH, and the disaggregated information on gender and age of persons with disabilities is also missing.

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<sup>5</sup> The basis of this brief overview is the Second Alternative Report on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities for BiH published in 2016. The report was to a large extent produced by persons with disabilities, including 65 organizations of disabled persons from five coalitions of organizations of people with disabilities. Report is available in local language at <http://bit.ly/2favd0B>.

There is no information available on children with disabilities who attend regular schools, which could be a good indicator of respecting the human rights of people with disabilities in the country through inclusive education. The laws of elementary, high school and higher education foresee equal right to education for all children, but because of the jurisdiction in the field of education or the lack of implementation of those regulations, children and youth - in particular with physical disabilities and mental disorders - are still excluded from the regular education progress. Due to lack of resources for supporting inclusive education and because of lack of awareness of the need to include people with disabilities in regular education, the government usually resorts to providing education for people with disabilities in special schools. There is also no organized system of early intervention.

The accessible environment, appropriate orthopedic, typhlo-technical and other assistive technologies and aids, teaching aids and school books, assistance in the class and other things are not ensured through the legislation. No budget lines are specifically allocated for the assistive techniques and aids. Specific financial resources are earmarked through specific budget lines for the functioning of special education schools and for children with disabilities (at entity level), but none such budget lines exist for inclusive education, which evidently demonstrates the attitude of the government towards inclusive education.

Early intervention and rehabilitation are not regulated by any special law, and the need to make preschool education available is not recognized, in particular for children with combined disabilities and for children from rural areas. Many children with disabilities from urban communities are not included in preschool education programs, even where this is regulated under the laws from this field.

The health care is limited for children with disabilities due to architectural barriers, lack of expert personnel for specific disabilities, and in particular inaccessible dental and other health care services for children and people with intellectual disabilities. There is a lack of programs for educating medical and paramedical staff for working with people with disabilities. There is also a lack of programs for adequately determining the needs for orthopedic and other aids, and individual needs of people with disabilities, as well as programs for ensuring hygiene materials.

Women and girls with disabilities still face multiple discrimination, they are excluded and isolated even from the activities of organizations of people with disabilities. Women are rarely heads of disabled persons' organizations, and have only recently started establishing more disabled persons' organizations that specifically bring together women and girls with disabilities.<sup>6</sup> They also face the risk of experiencing

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<sup>6</sup> Women with disabilities are underrepresented in public life and political decision making, none are represented in politics on any level of government, and even in the state-level Council of Persons with Disabilities, they make up just 20% of its members. Also, women with disabilities do not equally participate in the labour force with men with disabilities and make up just a quarter of all employed persons with disabilities in BiH. See more at Initiative for Monitoring of the European Integration of Bosnia and Herzegovina 2008.

violence against women and girls, as the prevalence of violence rates are the same for women with disabilities and those who do not have a disability.<sup>7</sup> Health services are not adapted to the needs of women and girls with disabilities, in particular regarding sexual and reproductive health.<sup>8</sup>

Disabled persons' organizations are not guaranteed support through legislation that would ensure they receive ongoing and adequate support from government institutions in order to provide services and support to children with disabilities and their families. The slightly different regulations of the two BiH entities discriminate against children with disabilities and their families on the basis of geographical location, as there is a difference in either financial value of benefits (e.g. disability benefits) or services (e.g. some do not exist in one of the entities). Despite existing regulations for the full accessibility to buildings and removal of architectural barriers, many public buildings (schools, culture buildings, sport buildings, buildings of public administration, health centers, centers for social work, etc.) were built and reconstructed without the implementation of the accessibility standards. No sanctions were issued for those institutions and companies that violated those regulations.

There is a tremendous need for implementing a comprehensive campaign on every level of government on raising awareness about the rights and equal opportunities of persons with disabilities, as well as including question of people with disabilities in every segment of society. The government still has a long way to go in harmonizing its legislation with CRPD, providing adequate funds to enable its implementation, training and sensitizing staff who provide services to persons with disabilities, as well as decision makers, specifically making earmarked funds available for accessible education and health services, and funding specific support services and disabled persons' organizations.

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7 The prevalence rate of violence for all women in BiH is 47.2% while for women with disabilities it is 48.5% (pp. 47 and 51). (Agency for Gender Equality of Bosnia and Herzegovina 2013:13, 47, 51.)

8 There are only four accessible reproductive health medical offices, but doctors and other staff are not trained on how to use the accessible equipment. (Sarajevo Open Center 2016:29) There is one organization in Sarajevo, XY Association, that provides medical examinations and advice for girls and young women with disabilities, including intellectual disabilities, but this is not part of regular health services and is not available throughout the country.



# 5. Research Findings

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The following sub-chapters present the research findings, each including a brief overview of the legal and policy framework relevant to theme discussed and if relevant, the extent to which it is implemented, as well as a presentation of findings on sub-chapter topic discussed including quotes from research participants and a conclusion on how the findings impact the lives of children with disabilities with recommendations.

The topics were construed based on patterns of themes that stood out in the research data, that were most repetitive and that impact the lives of children with disabilities and their families the most. These topics are: schools - in the function of a central life event in childhood, and key instruments for socialization and development of all children; services - as the crucial support mechanisms that enable children with disabilities to exercise their rights and become fully socially included; mothers and fathers in the role of assistants - an example of the impact of the lack of services on the life and development of children with disabilities, and the altered role of parenthood in their families; diagnosis and hospitals - diagnosis as procedures and hospitals as locations that have a fundamental impact on the lives of children with disabilities and their parents; financial situation - the theme of everyday life of families of children with disabilities who often fall into poverty due to expenses related to providing services themselves for the social inclusion of the children; ableism and the magic wand - the need to perceive persons with disabilities from an ableist point of view and the constant need and expectation that the disability needs to be removed in order for the children with disabilities to become socially included is a good introduction to the final topic of disabled society - with endless examples of how the society and its key actors do not create opportunities and spaces that can or are intended to include children with disabilities.

## 5.1. Schools

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The international commitment that ensures that every child and adult receives basic education - Education for All (EFA) - is based both on a human rights perspective, and on the generally held belief that education is central to individual wellbeing and national development.<sup>9</sup> The CRPD obligates governments to provide inclusive

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<sup>9</sup> UNICEF 2011:4.

education to all children, youth and adults with disabilities.<sup>10</sup> Development programs that support educational reform recognize that inclusive education is not only beneficial to children with disabilities, but also to all marginalized groups in a society, and propose that it is not perceived as “a philosophy or educational approach exclusively for children with disabilities, but as an approach that is fundamental to achieving the right to education for children from all marginalized groups – for example, girls, Roma children, or working children.”<sup>11</sup>

The legal and policy frameworks of BiH comply with the CRPD and state that inclusive education is the right of all children and youth with disabilities in the 65 laws at all levels of government<sup>12</sup>. These laws do not, however, obligate governments to allocate resources in their budgets for the enforcement of the education legislation, apart from funds for monitoring and coordinating these activities. Only sporadic allocation is made for teaching assistants, an internationally recognized mechanism for facilitating inclusion, and even that exclusively through the work of non-governmental organizations.<sup>13</sup> The legal framework is partially harmonized with the CRPD, with some room for improvement and specialization. There is a complete terminology inconsistency in use of the phrases relating to children with disability and instead of following the CRPD “children/person/people with disability” the BiH legal framework uses: children with special needs, children with special education needs, children with psychophysical issues, developmentally disabled children, etc.<sup>14</sup>

Inclusive education consists of a number of elements that are interdependent and necessary for it to succeed. Accessible education institutions (architectural and information accessibility), accessible teaching instruments and textbooks, trained teachers, access to teaching assistants, access to specialized experts (speech therapists, orientation trainers, etc.), development of individual programs, adapted curricula, sensitization of classmates and their parents, and support to parents of children with disabilities. Most of these are not available in schools in BiH. On average there are two to three elements in place, in rare cases one more, and in most cases, none.

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10 Although there are different schools of thought on which approach to education for children, youth and adults with disabilities is most effective and appropriate (segregation, integration and inclusion) the Article 24 of CRPD clearly states that “States Parties shall ensure an inclusive education system at all levels” (para 1) and that “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” (para 2).

11 UNICEF 2011:5. UNESCO argued that a broad concept of inclusive education “can be viewed as a general guiding principle to strengthen education for sustainable development, lifelong learning for all and equal access of all levels of society to learning opportunities so as to implement the principles of inclusive education” UNESCO, Inclusive Education: The Way of the Future, International Conference on Education, 48th session, Geneva, Switzerland, 25-28 November 2008.

12 In addition to these laws there additional legally binding documents on inclusive education such as strategies, action plans, and rulebooks that are not equally present on all levels of education and not equally defined in the legal and policy frameworks on all levels of BiH governments.

13 Somun Krupajlija, L. 2014:31.

14 Compliance Laws in Bosnia and Herzegovina with CRPD/Education – suggestions and recommendations, 2015:5.

Spatial and material conditions in schools are badly organized and inaccessible, there are existing information barriers and architectural barriers. Even when children excel at school, their equal access and participation is prevented due to partial physical accessibility, such as in the example of Aldin from Goražde:

"He is intellectually above average... He has all As [top grades] and rarely, gets one or two Bs... Regarding his mobility in school we ensured [all his classes take place in] one classroom and this does not require him to move floors... His greatest challenge in school is to be able to move independently, without assistance." Jasmina, teacher

"[The government] promised to make hand-rails and ramps to enable children with disabilities to climb to the second floor of the school, but it has never happened. This is one of the things that is an obstacle for Kaća on a daily basis." Zora, neighbor

It is not enough working on training of professional staff. During the process of teachers' education there are no subjects which would prepare them for the work with children and youth with disability.<sup>15</sup>

"Believe me, I was afraid to start... It was the first time in my 20 years of experience that I was expected to work with such a child [with disability]. ... In the beginning it was very difficult. ... Teachers who work with children with development difficulties admit that they are not sufficiently qualified or educated for what they need to do in practice. I have independently researched ways to adapt curricula to Anđela's needs. ... Organization of education for teachers would enable the teachers to face the challenges experienced in providing inclusive education for children with disabilities." Anđelija, teacher

"The teachers found themselves in unexperienced situation as most never had the opportunity to work with children with disabilities. There should be trainings for teachers ... there are more and more children in inclusive education and teachers are still not taught this during their university education."

"We are not sufficiently educated to work with children with special needs." Milica, teacher

"I think that the greatest obstacle is the [lack of] education of teachers of subject classes ...those teachers are still not sensitized." Tereza, teacher

Development of individual programs for children with disabilities is one of the cornerstones of inclusive education. The participants in this study shared the extent of the lack of support they face in accessing individual programs for their pupils with disabilities.

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15 Disability Policy in Bosnia and Herzegovina 2008:10.

"It [individual programming] is poorly defined ... even the defectologist does not know [how to adapt math curricula]. The process of approval of individual work and program is too difficult and should be started earlier [in the year]. Dajana has no individual program, she follows the existing one and I myself just skip things I see that she cannot do." Aleksandra, teacher

Mona's teacher, Minela, also faces technical difficulties in providing adequate education support. The greatest obstacle is that the Ministry of Education spends the entire first term in assessing individual programs for children with disabilities. Her teacher is forced to work with Mona as best she knows, but without any legislative or policy basis, which can also lead to a court case against the teacher or school or both, and thus she makes no notes during the first term on Mona's progress.

Teaching assistants are another crucial part of the success of inclusive education. They are not foreseen in the legislation at all government levels, and are thus usually provided through non-governmental organizations, paid by parents or include parents in the role of teaching assistants.

"In the beginning children would ask why Andrej's mother is in the classroom, but later they got used to her [being his teaching assistant]. [His mother] Zorica is very patient and is sensitive to children and that has helped a lot." Tijana, teacher

"Lucija is part of inclusive education, but I think that society should provide [teaching] assistants who could guide children with special needs through school. In this case, it is the parents who have engaged me as a personal assistant ... for 7 years ... but I have no rights, no contract with the school, nothing. I mean I would like the children to have teaching assistants, but also for teaching assistants to have employment." Katarina, education assistant

"Problem is the lack of teaching assistants. We waste the whole first term until a teaching assistant is approved, which makes it a huge problem for the teacher, because Mona sometimes needs to leave the classroom and the teacher cannot leave other children alone. In the second term, she has an assistant, but her parents pay for it." Minela, teacher

The inclusion approach in BiH schools often does not include work with classmates and their parents. Ideally they should be informed about the child with disabilities, given some guidelines on how to be a sensitive fellow pupil, and provided space for questions and answers. There are some positive best practice examples where school management and teachers did work on creating an enabling environment for children with disabilities.

"The children really accepted Aljoša so well! I know that in the beginning they had a Parents' Meeting and that Zoran and Bojana [Aljoša's classmates'] addressed parents, explained to them ... and this surely had a [positive] impact ... We leave him alone

with other children during breaks and it works out extremely well. When they play outdoors he is included in their games ... he is included in his own way." Adrijana, teaching assistant

"Amin's teacher was a real enthusiast. She did so much to make the whole class accept him for who he is. She prepared the classmates [with information] about his illness." Azra, defectologist

"The teacher was surprised to see that I came to school whilst I have mobility difficulties. She said she needs time to prepare my classmates for my arrival and explain to them how they can assist me. The first day I entered the classroom I received a huge applause and smiles. ...I never felt different, I was always part of all the school trips and all the pranks." Sanja, 15 years

However, there are experiences of children who were included in schools in a way that immediately made them feel different and out of place.

"There were some difficulties with children... who did not have the opportunity to meet children with development difficulties before... It was strange for them that a child with no speech can go to school with them ... sometimes they used to say: 'She is stupid! She is silly! Why should she go to school if she does not know things like we do?'" Minela, teacher

In this study, we also encountered some teachers, experts, and parents who do not support inclusive education, most often because it was not implemented adequately in the case of their children with disabilities.

"This inclusion, this inclusion has brought more suffering... like it is great ... Well, maybe in the part of bringing children into the school, to spend time with other children, but you cannot expect a teacher to manage that child with another 25 pupils. A child with moderate intellectual disability can succeed only with the support of a defectologist or speech therapist or teaching assistant. I do not support special education, but inclusive education without experts is meaningless." Mirela, speech therapist

"Inclusive education should mean that there is a teaching assistant, adequate teaching materials and an adapted curriculum that should be accompanied by adapted textbooks. We have none of this." Anđelija, teacher

"We tried social inclusion. It is impossible. They did not have teaching assistants ... this does not exist even today, not even a defectologist. They do not exist in schools while they are necessary for inclusion." Mirsad, father

Those teachers who support inclusive education face barriers such as lack of support on developing individual plans and programs, getting support on specific support that could be provided for different kinds of disabilities. "I think that inclusion is a

good step forward. ...I support inclusion because [in addition to destigmatizing children with disabilities] it [enables other] children learn to empathize, to learn humanity." Minela, teacher

The experience of implementing inclusive education in BiH schools has shown the positive impact it has on children with disabilities, as it makes them less stigmatized, and more socially included. There were many examples of acceptance and inclusion of children with disabilities in their classrooms and with their classmates in this study. These experiences were shared equally by teachers and experts working with children, their parents, their classmates, as well as children themselves.

"Children sympathize with him, but have no pity, they provide him support, accept him the way he is." Azra, defectologist

"For me the greatest success is this acceptance. ... When you enter the classroom that includes a child with disability, and children hug each other and support her, it is a huge success." Anđelija, teacher

"Whenever Andrej accomplishes something in class his classmates applaud him." Zorica, mother

"Her friend in preschool does not exclude her, for all school plays and recitals she is always there [included]." Đina, mother

"Last week I did not go to school on Thursday and Friday. I will go tomorrow. I go every day to school and attend all classes. I love school a lot. In school, you sing, learn English..." Dajana, 11 years

"My best friend is my classmate whom I met in school. I am friends with her and we play together in school." Kaća, 11 years

"When Amin comes, I give him a hand in taking out his books and putting them on the desk ...sometimes he plays games on my mobile and beats my high scores ... I help him if he needs something... but I am not alone, other children support him, too." Mia, friend

This study has confirmed the existing findings that the success of inclusive education in BiH currently rests solely on the willingness and interest of individual professional staff (teachers, speech therapists, defectologists, etc.) and parents of children with disabilities. It has also contributed to the existing conclusions on the lack of capacity of BiH governments to implement the existing legal and policy frameworks that would enable the children with disabilities to enjoy their right to education. Despite many good experiences and best practices that can and should be replicated, each of the stories told by the children with disabilities, their parents, education staff, neighbors and classmates always had at least one example of an obstacle they face in accessing their school on a daily basis. There were also stories

of children who do not have any access to education. The governments at all levels, and in particular those with a mandate for the education sector,<sup>16</sup> need to provide adequate funding for schools, training institutions and universities, and local authorities that will ensure inclusive education is implemented in its entirety: trained and sensitized staff, adapted curricula and teaching instruments/textbooks, quick and user-friendly development of individual programs, physical and informational accessibility in education institutions, expert support staff, teaching assistants, and the development of an enabling environment with classmates and parents. School management and staff are equally responsible to take on the inclusion process with understanding and commitment, create enough space for staff to participate in trainings, lobby for adapting schools and acquiring accessible equipment, teaching aids, and teaching assistants. The teaching staff has a crucial role in motivating other children, their parents, and the wider community as part of an inclusive society to provide a dignified and enabling environment for children with disabilities and their families.

## 5.2. Services

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The purpose of introducing the community-based services model is to establish a system directed at supporting person with disabilities in achieving and maintaining optimal level of independence and social participation. In such a system, clients have access to various services which allow them to make decisions about their own way of living. People with disabilities should have equal access to everyday services in the community (regular education, health care, employment and social services).<sup>17</sup> A significant number of studies, supported by commitments expressed in key strategic documents and reforms trends in social protection, health care, education, rehabilitation, training, employment, independent living and everyday activities, indicate that the most appropriate approach under current conditions in BiH will be one based on a mixed model, including a range of local services and financial forms of support and services that take into account the specificities of different categories of persons with disabilities.<sup>18</sup> There are some services that are provided by authorities or in cooperation with non-governmental organizations in some parts of BiH, but they are not readily available in all municipalities or cities, and/or are not available for different kinds of disabilities based on the type of disability or origin of disability.<sup>19</sup>

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<sup>16</sup> Cantonal ministries in the FBiH and entity ministry in the RS.

<sup>17</sup> MyRight – Empowers People with Disabilities 2011: 25.

<sup>18</sup> Ibid. p. 33.

<sup>19</sup> Ibid. p. 7.

The results of this study show that these services are not yet available to children with disabilities, and in cases when they are available, the services are not adequate, not frequent enough or not provided by sufficiently expert staff.

“You will get the diagnosis on an A4 paper from the government and they are done with you. For everything else you have to fight on your own. ... I know a multitude of people who have sold everything and moved from one country to another in order to provide at least an inkling of what is possible for the child [with disability].” Edo, father

“All levels of government treat children like my Kaća as if they are invisible,” is how her father starts his story with tears in his eyes. He believes that Kaća and children like her [who have a disability] are the responsibility of the government, but that authorities have been providing hardly any support at all. Lucija’s family also came across great obstacles when trying to receive support guaranteed by the existing legal framework, given that the support or assistance received was only achieved based on friendship ties, or individual good-will of persons they dealt with. Each step of the way - getting a ramp for the school entrance, getting a teaching assistant - was made possible owing to compromise and willingness of individuals. This experience is shared by many other parents of children with disabilities.

“Last autumn, I went to find out how we can obtain our rights based on that law, given that I am linked to relevant ministry through my job. The lawyer at the Ministry told me: ‘You are always looking for something, and where is the money for that?’ Thus, you have an adopted law that is being violated by the ministry in charge.” Slaven, father

“The social worker [from the Center for Social Work] recommended Mjedenica<sup>20</sup> to me. We called Sarajevo, we went to Sarajevo, met the teacher, defectologist, and social worker, and they said that they would call back. They never called back so I called them and they said that they could not accept her because there was no space. One staff member is in charge of six children.” Safeta, mother

Social protection services are limited to administrative processing of requests for cash benefits and assistive technologies. Centers for social work, in general, seem to be taken up with bureaucracy with little time left for support to their users, including families with children with disabilities.

“I imagined that there is some kind of a team in the Center [for Social Work] that would visit us and ask for our needs, give us some advice. We were visited by a social worker only once and only because it was their obligation during the categorization procedure.” Bojana, mother

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<sup>20</sup> Mjedenica is the short name for the Public Institution for Special Education and Upbringing of Children "Mjedenica" in Sarajevo.

"I think that there should be some kind of notice, at least on a monthly basis, to invite parents, have a meeting and to present what are the rights we are entitled to. I have the feeling as if everyone is considering me misfit, I don't feel comfortable when I go up there [to the Center for Social Work]." Đina, mother

Parents of children with disabilities mention other services that could be very useful for children, such as summer camps, where children could express their talents and abilities through individually tailored programs.

Support of local non-governmental organizations in providing social services for children with disabilities is affirmed by a number of parents who are grateful for their support. Andrea arrived completely non-socialized to the "House of Hope", and after six months of her visits there she became adapted to working in a group. They provided her with musical therapy because they noticed that she responded well to music." Safeta, mother

Even when there are no local non-governmental organizations, parents of children with disabilities have use of those that are active on a regional or national level. Given that the information provided by the doctor was limited and insufficient, Mona's mother - in addition to spending all her time researching the future development of her child on the internet - attended the workshops organized by the Association of "Life with Down Syndrome" from Sarajevo.

Amin's mother, on the other hand, thinks that there are not enough organizations and day centers for children like Amin in Lukavac. "There should be more of them, they should have workshops, there should be day centers for such children. For instance, internet colleges, long-distance learning, so that those children can continue their education." Almira, mother

However, even the invaluable support provided by the non-governmental sector is not a guarantee that it is sufficient or that its continuity is guaranteed. "The greatest support for me is the Association, although we can take them there only once a week." Bojana, mother

"After Andrea grew out of pre-school age she goes to "House of Hope" only once a week. A speech therapist and a defectologist work with her only half an hour each." Safeta, mother

There are parents who did not have good experience with the services provided by the non-governmental sector or who believe that those organizations lead to further segregation of children with disabilities.

"These children [with disabilities] need to be included in a healthy environment, because that can enable them to have better results. I think that in the Association they do not accomplish good results, because they do not socialize children and do not teach them social skills." Mišo, father

"Višnja is not going [to the Association] because she is rejecting it ...simply the environment does not suit her ... it affects her psychologically and she does not go to the defectologist sessions there. But I know of children who do go to that defectologist." Tereza, teacher

"She was included in the local Center for Upbringing and Education. The center was established based on the work of us parents who are from the Association, we wanted to establish a center like that. However, my Višnja was not happy there. She would be ok during the physio-therapy...but when they would take her to sit among other children, they all have some tics, screams, it is loud and after 15 minutes they bring her back to me." Magdalena, mother

"I took her there but she had a repulsion towards that Association. Why? She could not look at 'those children', she felt tense, she would be tense and so we did not take her there any more..." Zorica, mother

Medical services and assistive technologies are also not readily available to children with disabilities. The obstacles faced in accessing them are at times due to the physical inaccessibility of health institutions. For instance, although Amin's parents were satisfied with the physio-therapy treatment provided to their child with disability in the Health Center Lukavac, his mother Almira said that "going there was a hardship because of the architectural barriers."

Parents indicate that there is a lack of a holistic approach to service provision, that there is usually one service, but not more of those that are required. "We had access only to those treatments that existed in Bijeljina, and to those treatments that were accessible at national level and which we did not have to pay. This was the speech-therapy service. However, we did not have access to any other services, nor do they exist in Bijeljina." Slađana, mother

Equally if there is a service, it is not available as much as it is required for the child with disability. "It is very difficult for them [the family] because the rehabilitation provided is not sufficient. There should be rehabilitation at least three times a week so that children could achieve better results, and once a week is very little. The authorities in charge should take care of this, and provide adequate rehabilitation." Mile, family friend

"Kaća lacks access to rehabilitation spas, like the one in Banja Koviljača or access to a pool." Kaća's mother

Some parents come across negative experiences in one health institution, but have very positive experience in another, showing that although there is lack of sensitivity and expertise there are examples of good practices, too. When Andrej returned to Zvornik, it was recommended that he received speech therapy treatment in the hospital in Zvornik. However, speech therapist in that hospital rejected to work with Andrej, because Andrej was not adequately 'prepared', and the therapist suggested

Andrej is taken to Bijeljina for therapy. The parents did take Andrej there and say “the visits to Bijeljina for the speech therapy treatments helped us a lot, they were preparing Andrej very well, and he was part of the groups, too.” Saša, father

However, the negative experiences with health institutions and their capacities to provide adequate services prevail. “I brought the diagnosis from Belgrade which states ‘Božana requires treatment at least three times a week’. I achieve more with her in one month of continuous work in Belgrade than here [in BiH] in half a year. ...because they work with her just for half an hour ... I mean I have nothing against them [local service providers], but so much more work is put into supporting children [with disabilities] in Belgrade ...45 minutes with one therapist, then a 20-minute break, and then 45 minutes with another therapist.” Đina, mother

“I used to take her first to the Psychiatrics ward here, but I was not satisfied. ...then we heard about Makarska, that there is a Center there, a private one. We took her there for a year, every day, apart from Saturday and Sunday.” Magdalena, mother

“Every time when we went to Banja Luka [for services] we were told that he would never be able to learn to speak in Bijeljina. ...they [doctors] insisted that he had to attend the School for children with hearing difficulties in Banja Luka and we accepted that...but the condition was that he is placed in a care family. We insisted that we live with him in Banja Luka but they said that this was not according to law. To me it is not normal at all. In the end, we gave up.” Dragan, father

Access to assistive technologies is also limited, and even when there is access to them they are of poor quality or are rarely replaced. “Amin’s electric wheelchair were not received from the community [authorities] but it was a present from a fellow citizen who works in Germany. The Institute for Health Insurance of Tuzla Canton does not provide wheelchairs for children like Amin.” Almira, mother

“One could get a wheelchair from the health insurance, but they are not adequate, they are just a basic model and are not adapted to Lucija’s needs. Thus, we would have to top up the wheelchair at a very high price. Lucija gets her wheelchairs as donation from Irish pilgrims who come to Međugorje, whom we met through our friends. When Lucija outgrows her wheelchair, we pass it on to another child with disability.” Slaven, father

Another father mentioned the difficulties of importing supplements and medication that are not available in BiH. “We had problems importing the supplements from the States, our customs made a problem. I understand them, too, they say ‘how do we know, it could be some kind of drug.’<sup>21</sup> But we raise funds for them, because the supplements are really expensive, and then we can’t import them.” Zoran, father

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21 The customs are obliged to open all suspicious parcels, and if they do so they have to charge for their services. Also, an individual is not allowed to import more than 50KM worth of goods, including postage.

Access to teaching assistants is also varied, most frequently they are engaged by the parents. Sometimes children with disabilities do not have a teaching assistant because it is not prescribed by the law for their type of disability. "I am a teacher and I have a child with disability in our class and she does not have a teaching assistant. My heart aches for her because I cannot dedicate sufficient time to her because of the other children in the class. I think that all children who need one, should have access to an [teaching] assistant." Zoran, teacher

"We tried engaging a teaching assistant for Anđela, but it was not possible because in RS only children with autism and children with physical disability have a right to a teaching assistant." Branka, speech-therapist

Specialized services that children need are often discovered by the parents of children with disabilities. Some manage to find access to such services, but others do not. "Now we are using the hyperbaric chamber in Banja Luka, it is now free of charge in Zotović<sup>22</sup> ... we have access to neuro-feedback, speech-therapist, creative workshops and musical therapy." Zoran, father

"There is a treatment for saliva leaking. It is a massage of the inside of the mouth and the bottom part of the tongue and inside of cheeks. That massage helps stop saliva leaking and this service exists in Croatia, but not here. It is not accessible for us because of lack of funds. ...I met parents from Zagreb whose child was successful in stopping saliva leaking through that method. Our daughter cannot control that, no matter how much it bothers her. I tried to do it [the massage] while she brushes her teeth, but I don't know how to do it." Zdravko, father

Another worrying obstacle to accessing adequate services for children with disabilities is the lack of expert training and sensibility among service providing staff. "The team [mobile team] that was supposed to visit is nowhere to be seen. They have no experience; they were scared in the beginning. They need to be trained, there need to be more human resources." Bojana, mother

Even teaching staff and assistants admit that they lack adequate training to work with children with disabilities. "We attended the Duga [NGO from Sarajevo] workshop. Then we tried to, sort of, make those individual plans and programs...but we do not have a defectologist in our school, so it is a big problem for us." Tereza, teacher

"I do not have some formal education, but the practice in the Association was just amazing for this job." Adrijana, teaching assistant

"We heard from the surdoaudiologist that she has very little time, almost no space for additional training. ...If she does attend a training it is usually something that she decided to do and pays for it privately. We heard a similar story from the teacher. She

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<sup>22</sup> Zotović is the abbreviation for the Institute for Physical Medicine and Rehabilitation Dr Miroslav Zotović in Banja Luka.

usually taught herself, researched, sought information on her own..."Slađana, mother

Some service providing staff are just insensitive to children with disabilities, and unaware of their lack of awareness. "Andrea is a scared little girl who avoids any physical contact. If I touch her hand she releases screams." Aldijana, speech therapist

The role of the BiH governments at all levels is significant in creating the needed changes in developing and providing services for children with disabilities. The non-government sector, including organizations of people with disability, has played a key role in creating some services, bringing into light the failures of the system, and advocating for the needed changes.

The authorities in BiH are obliged by the Constitution of BiH to implement the guaranteed human rights. The biggest challenge for BiH governments in implementing the CRPD standards for service provision is the poor allocation of financial resources. The scope of these rights, especially social (financial) support, as well as support to other services, needs to be improved in Bosnia and Herzegovina in all areas discussed: social protection services, health services, assistive technologies, specialized services, and continuous education, training and sensitization of staff working with children with disabilities.<sup>23</sup> The government needs to provide adequate financial resources, but also an enabling environment for the development of those services: such as licensing organizations which have capacities to provide those services, encouraging education and specialization of expertise, and including persons with disabilities in the development and planning of the services.

### **5.3. Mothers and fathers in the role of personal and educational assistants**

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Despite its legal obligations, BiH governments and local authorities do not provide the basic support services for persons with disabilities, in particular for children with disabilities - when these services can have such an important impact on their development, social inclusion and independent future. In the absence of adequate government service providers, the tasks of providing these services are to some extent taken up by non-governmental organizations, but sporadically and not equally in all areas of BiH.<sup>24</sup> The families of children with disabilities play the greatest role in replacing those missing services, both through their engagement as human resources, but also through finding and financing experts for some of the services.

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<sup>23</sup> Ministry of Human Rights and Refugees. 2012. *The report on implementation of the UNCHRPD in Bosnia and Herzegovina, according to article 35., paragraph 1.* <http://bit.ly/2g7jqRb>

<sup>24</sup> MyRight – Empowers People with Disabilities. 2016: 9, 21, 26.

Although this is not a quantitative study it is necessary to report that this is the only topic in the entire research where each of the individual stories included the examples and experience of parents, in particular mothers, as replacements for the lacking government services for children with disabilities. In addition to the standard role as a parent, in families of children with disabilities one or both parents take on the roles of: carer, teaching assistant, personal assistant, sign language interpreter, and in some cases, even the role of a teacher.

“They need to be supported. They need to be financially helped because those children cannot earn their own salary. They cannot even use the bathroom on their own. The parents have to do everything.” Zijada, neighbor

The mother is familiar with many treatments that are not accessible to Aljoša and Andrej. There are no ABA therapists, experts for Floor time, for the TOMATIS method, The Son-Rise Program, PECS, TEACHH, therapeutic horseback-riding. Although some people tried to use these methods, they were not qualified enough. “It would be so important if we could have access to services that include these methods of work, we would not be wasting so much time in researching and looking for information.” Bojana, mother

“All doors seem to be closed for them. Some parents are more engaged and they advocate, but most are in a difficult situation and it is the mothers who are most often left to manage [the support for their] children with disabilities. The mothers are often emotionally and physically drained, you cannot avoid sympathizing with them...” Ivana, neighbor

There is an overwhelming evidence of mothers taking up the greatest burden of supporting their child with disability, either in specific home-based treatment for children prescribed by medical professionals, or as a replacement for lacking services. Mothers are often those who accompany their child with disability to medical treatments in hospitals, non-governmental organizations or help do them at home.

“Mother does the treatment exercises with Aldin all the time. In the beginning, we took him to Goražde for treatments, but because it was taking up a lot of time and money, and the therapists said she could do the exercises with Aldin, we stopped going there. Now she does the treatment exercises for an hour every evening. She does not feel her hands [due to the strain of the treatment exercises].” Halid, father

Andrea’s mother also dedicated her time to driving her daughter to treatment exercises in “House of Hope” in Odžak from Prud, a 16-kilometre distance. She would then go home and drive back to pick her up again. For a small rural area travelling 16 kilometers four times a day was a hardship for both Andrea and her mother, but despite the difficulty her mother Safeta is grateful and satisfied with the treatment exercises Andrea was getting in “House of Hope.”

"We are still exercising on the exercise mat every day. The only difference is, of course, that you cannot [do as much] when she weighed 10-15 kilograms and now that she weighs 50kg. Now it is physically more of a strain for both me and her." Marijeta, mother

Obren recalls how the whole family found it very difficult to cope with the diagnostic process for Zorica, but that it was the mother who bore the greatest burden. "It was horrible. For a long time, it seemed that she would be hundred percent disabled. You would cry whenever you spoke about this on the phone. We could not do anything, could not sleep, we were constantly thinking about what would happen. Mother was with her. She is the one who endured all of those tears and fear and everything..." Obren, father

Amin is a 12-year-old boy who attends a mainstream school, but as he cannot control his sphincters, the school calls his mother every time he needs to go to the bathroom. His mother comes to the school to help him relieve himself, but sometimes they have to go home. It is often a problem because he suffers and feels uncomfortable while he waits for his mother. His friends try to entertain him to keep him from thinking about having to go to the bathroom. There are numerous other stories of how mothers replace teaching or personal assistants.

"Due to his development delays Andrej started school later than other children. His mother is with him during class, sits with him and assists him. His mother sometimes leaves the classroom for fifteen minutes, for instance when children are drawing." Tijana, teacher

"Mother Safeta is overwhelmed from supporting her. Andrea cannot even hold a spoon [on her own]." Nikola, neighbor

"When he would begin to protest, his mother knew exactly how to calm him, and since she is with him everything functions extremely well. Zorica is a good woman, she has a feeling for children, his classmates have grown to like her. They will come up to her and ask her to tie their laces, open a bag of chips. In the beginning, I was afraid how it would turn out, but it is important she is such a person that is good with children. A [teaching] assistant is a key element, and he really needs one." Tijana, teacher

Daris communicates best with his mother and she has the role of some kind of "interpreter" for him, but also motivator for some form of social interaction with other classmates. "My wife has an immense role in all of this [support to Daris] and she spends most of her time with him. She is exceptionally dedicated to Daris and informed about that problem [of his disability] and puts in a lot of effort. She is absolutely irreplaceable in the whole process [of supporting Daris] ... Mothers are those that bear the greatest burden ...I also know many cases where mothers take care of their children [with disabilities] because their husbands have left them." Edo, father

Parents themselves are aware of the extent of support their child with disability requires and that it is the parents that are the only available option to provide that support. "I have to change her; I monitor every move she makes. I have to help her sit down. If she needs to wash her face, I also help her. If she wants to eat, you can give her some food to eat herself, like potato chips, but everything else I feed her." Magdalena, mother

There were some examples of parents being assigned to be teaching assistants to their children by government institutions, and fathers taking up that role. The responsible ministry responded well to the request of the family that the father is the child's teaching assistant, but more in the role of personal assistant during study. "I study with her, take her to school and back, and spend time with her during the breaks, but I am not there during class. I also take her to the bathroom. Perhaps it would be easier if I was there during class as well, because she cannot follow everything that the teacher says and cannot write as quickly. Then I manage as best I can, I copy from other kids during the break in order to make up for the missing time." Zdravko, father

In another family, the parents also divided their roles so that the father is the one spending time with the child with disability. "Mišo is now retired and dedicated to Srdjan. He chose early retirement in order to support the child. The mother still works. They divided their roles - father is taking care of the child and finances, and the mother is taking care of the work and housework." Biljana, researcher

Some of the parents are aware that their role of teaching or personal assistants might not be beneficial for the further development of their child with disability, particularly during the process of becoming independent.

"Andrej directs his look always at me. When the teacher calls him [to the blackboard], he first looks at me, and then I tell him to go to the blackboard. Every step, every question he first turns towards me. I wish we could make him more independent so that I do not have to be with him all the time. This is currently my greatest wish ... that he is more independent, that he does not expect me to monitor every activity of his. I am trying to make him independent, but it is very difficult to find the right balance." Zorica, mother

Children with disabilities also recognize the significant role their parents, and in particular mothers, have in enabling their further development.

"I play with Barbie dolls with Marta. Mother and I draw every day. When I am bored, I draw - actually my mother draws - I just take the markers and color in." Lucija, 15

"My mother takes me to school." Višnja, 15

"I often think as to why did this happen to me, why am I like this. I get sad, but my mother is always there, she is the one who gives me the strength to fight for a better future." Sanja, 15

When there is a lack of necessary services, which BiH has legally obliged itself to provide to children with disabilities, parents are frequently overwhelmed “because many feel ill-equipped to deal with the realities of effectively handling the child’s physical, psychological, and/or educational needs. In addition, children with developmental disabilities are more likely than children without disabilities to develop behavior problems, creating further parental stress and depression.”<sup>25</sup>

“It is very, very stressful, [stress] is the most difficult thing of all. I try to forget at least for a moment, but it is difficult to forget. I go to bed thinking of her, of her future, I wake up thinking of her, she is always on my mind. She is the only thing on my mind, all the time, what will be of her when I am not around.” Safeta, mother

It is true that parents are children’s first teachers, but the role of the local authority, government institutions and services should be focused on facilitating this process for parents of children with disabilities as much as possible by creating an environment in which every child could reach their utmost.<sup>26</sup> It has already been reiterated that it is mandatory to make adequate legal and policy frameworks, including accompanying budget allocations, that will provide regulation and procedures for the provision of adequate support for children with disability in the local community.<sup>27</sup> Partnership of professional workers and teachers in inclusive schools has an important role as the parents are the those who introduce their child with disability to their first experiences and in doing so, affect the child’s development in the period of education. Parents want to be more actively involved with teachers and other experts when it comes to development of optimal potentials for their children with disability, but it is the education sector that needs to create a space for the partnership between the parents and professional workers.<sup>28</sup> Programs need to be introduced that will provide parent education in BiH, which are usually readily available for parents with typical children, but not for families with children with disabilities. These programs have been developed and used and have shown to lead to “positive outcomes for both parents and children by reducing negative child–parent interactions and subsequent behavioral problems and increasing positive interactions.”<sup>29</sup>

## 5.4. Diagnosis and hospitals

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Being a child with a disability means that some part of childhood, or in some cases even all of it, is marked by constant medical examinations, surgeries, tests, visits to hospitals, health centers, and generally spending a good deal of one’s earliest years

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25 Emerson, E. 2003:51–58.

26 The Institution of Human Rights Ombudsman of Bosnia and Herzegovina. 2010:48.

27 MyRight – Empowers People with Disabilities 2011:33.

28 Karapuš, Sahmanovic and Masovic. 2015:18.

29 Reio and Fornes 2011: 53–61.

in the company of doctors and nurses. This sub-chapter presents the extent to which children with disabilities are exposed to continuous and/or intense hospitalization, and the proof of the impact it has on their everyday lives, families, and exclusion from society.

The acquisition of an adequate diagnosis for many children with disabilities is a lengthy process that is also nerve wrecking for their families and often painful and confusing for children. The diagnosis process starts for some children from the moment they are born, while with others - who acquire their disability at later point in their childhood - the diagnosis starts later. The sub-chapter will also present cases that show how parents feel lost in the labyrinths of diagnosis procedures, how they are left to deal with this process alone, that the length of the diagnostic procedures in some cases spans over not one but more years of childhood, and the overall lack of support for adequate diagnosis processes for both children and their parents/carers/families in BiH.

In addition to the general legal and political framework that protects the rights of persons with disabilities as described in chapter 7 above, the specific access to health protection and health insurance for children and other persons with disabilities is secured through key laws that regulate this sector, as well as more specific laws that deal with the rights of patients, dentistry services, and assistive devices at the level of FBiH, RS and BD. Recent research clearly identifies the lack of harmonization of this legislation with the UN Convention on the Rights of Persons with Disabilities in all of the 63 analyzed laws in FBiH, RS and BD.<sup>30</sup> The monitoring undertaken for the first Alternative Report on the CRPD implementation in BiH included visits to 64 health institutions throughout BiH and the analysis of accessibility for persons with disabilities showed that not even one of them was fully accessible.<sup>31</sup> Although 42% of the institutions did have accessible ramps for the entrance, 72% did not have an accessible toilets and 99% did not have information in formats accessible for blind and deaf children or persons with disabilities. Other significant findings relevant for children with disabilities were that the main obstacles in accessing health services include the: lack of or the inability to adapt diagnostic equipment and instruments, in particular for those with most severe disabilities; lack of access to specialized medication that could reduce or slow the onset of or increase of level of disability including specialized diet, maladjusted dentistry services for children with disabilities; lack of training programs on supporting children with disabilities in health protection for medical and paramedical staff, lack of medical rehabilitation programs (for all persons with disabilities); and lack of adequate program of determining the type and quality of assistive devices, tailored to individual needs of each child with disability.<sup>32</sup> Children with disabilities do not automatically have

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30 Include - IN project. 2014. *Analysis of Harmonisation of BiH Legislation with the UNCRPD - Health Working Group*. Banja Luka: IN project.

31 MyRight – Empowers People with Disabilities. 2016: 17-18

32 Ibid. p.27.

access to health protection, but are awarded this right through other laws, such as health protection for all enrolled pupils in schools or through the health protection awarded to them as dependents of employed parents.<sup>33</sup>

The children with disabilities, their families and neighbors, share their experiences of using health services in BiH. Stories of children who had to undergo lengthy and complex medical treatments talk of the frequent and long visits to hospitals. Aldin was subjected to surgeries from birth and often stayed in the hospital (away from his home town) for long periods of time, at times as long as 6 months. His mother recalls:

"I used to stay in Sarajevo [hospital] for as long as three months without going home, or for a month or month and a half, or for 20 days, but never less than 20 days." Kadira, mother

Another girl, Nevena, although she initially spent only one week in the hospital where she received eye surgery, overall she "spent most of her childhood in hospitals and visiting different medical specialists [in hope they] who could find a cure for her illness...she lost part of her childhood" Branka, mother

Families of children with disabilities are subject to seeking support and health services beyond their home towns and even across international borders, searching for the adequate health expert or health institution. In a number of interviews parents recall how "there is no place where we did not take her/him" and specified all the different venues they had to travel to "Orašje, Osijek, Zagreb, Sarajevo...we drove her [everywhere]..." (Marko, father.) Some families try to make an event out of the scheduled hospital visits

"When we go for therapies to Vienna and Zagreb, we make a trip out of it, and make a program beyond the hospital one, so that Lucija adores traveling." Marijeta, mother

Some parents are concerned that the time spent in receiving health care is time lost in school and with peers. Although there possibly are programs to mitigate this loss, none of the interviewed children had the experience of getting some form of education while staying in hospitals.

"He was absent [out of school] because of the time he spent in hospital and due to the testing and therapies he was subjected to." Amira, mother

Hospitals are not always equipped with adequate staff expertise or equipment for specific health services children with disabilities require, and one story reflects how the lack of basic equipment can even contribute to the development or exacerbation of a disability.

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<sup>33</sup> Ibid. p.28. Some local communities, such as Sarajevo Canton, provide health protection to all persons of disabilities, but they are an exception.

"They had a primitive incubator ...I was in the waiting room when the nurse called out 'Come to help!' Dajana was throwing her little hands about, the nurse could not open the [oxygen] bottle. She was calling me to help her do it. It was broken. She was without oxygen. They brought a hand pump and pumped [oxygen] during the entire first shift. They had no staff..." Zdravko, father

Parents also often complain that children were not referred for regular check-ups or for specialized examinations and tests and that this might have contributed to more severe disability consequences.

The most poignant reflection of the experience of receiving health services for children with disabilities in BiH can be summarized in the sentence of one of the girls with disabilities who was interviewed: "To me hospital is YUCK!" Višnja, 15

Such inadequate health services also mean that the process of getting a diagnosis for a child can be a very lengthy, tiresome and difficult time for both the child with disability and their family members. "There were many tests, re-testing, reading of results, visits to doctors, different views and conclusions, various suggestions, all kinds of things." Amira, mother

Parents experienced doctors who were unwilling to recognize that their children were not developing adequately.

"The pediatrician examined them, said that according to her they were neurologically sound, that they were spoilt, that twins are often late talkers because they develop a language of their own, that no reaction was necessary until they turned three years old, that they are boys, and that they [boys] are always late talkers...From her [doctor's] point of view all was well!" Bojana, mother

The parents of those children lost over a year before the children were diagnosed with autism. The length of getting a diagnosis for another child with disability lasted as long as five years, from 2009 until 2014.

Most of the parents had poor experience with the level of expertise of medical staff for the specific disability of their child during the diagnosis process. Some parents went as far as to Germany in order to receive adequate medical treatment. Many of the interviewed parents had very good experience with services provided in particular in Belgrade and Zagreb, as well as other locations where there are more qualified staff and institutions equipped with adequate health services. Some parents also find that there are adequately experienced staff in Banja Luka and Sarajevo.

"It really depends...We came across people [medical doctors] who were experts and knew their job, but there were also those who were completely lost." Bojana, mother

Parents of children with hearing loss had the experience of speedy and adequate diagnosis:

"Božana was born ... with a C-section. Hearing screening was done three days after birth that showed signs of hearing problems. Detailed examinations followed and when she was six months old audiology diagnostics (BERA) was done which determined a severe hearing loss..." Đina, mother

The diagnosis process is physically and emotionally difficult for children with disabilities, but also for their parents. The experience the parents go through is like that of denial but also "having a feeling like that of losing a normal child through death"<sup>34, 35</sup>

"When I discovered what was at stake it was very difficult for me. We didn't know what that meant. We were not informed in detail. Then we found out that very little can be done about it and that it is a lifetime problem. Our life stopped in a second. We neglected the other two children, we were only fighting for her." Zdravko, father

"Our reaction to the diagnosis was - why me? I was looking for the guilty party for what had happened...but when you become more engrossed in the problem you realize you cannot be selfish and ask why me." Elvira, mother

"When you get information that there is no help for them but that you have to live and help them for as long as you can, it is stressful. Like someone tells you that you got cancer. You go on, day by day..." Mirsad, father

The health services in BiH are not developed having in mind the support persons with disabilities have, and in particular the support required for children with disabilities. In order to provide adequate services, the health sector needs to develop cross-sectoral early identification of disability programs for children, and also review the capacities of: medical and paramedical staff (general staff to recognize disabilities, and specialized staff to further specialize in disabilities, to be aware of anti-discrimination principles and be sensitive to children with disabilities); health institutions to provide adequate physical and informational accessibility to children with disabilities, to create child and disability-friendly environments, and to have necessary and adequate equipment and medication to suit their needs; institutions in charge of assessing the need for assistive devices and purchasing them in order to ensure those are always suited to the specific needs of a child with disabilities; diagnosis processes and provide a "one-stop-shop" where the entire process can take place, as well as take into account the need to support the families of children with disabilities and their emotional and psychological challenges during the diagnosis phase.

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<sup>34</sup> Nyoni and Serpell 2012.

<sup>35</sup> "Being told that your child has a disability can be as traumatizing as learning of a family member's sudden death. Many parents are stunned by such news. Receiving such a message can produce overwhelming emotions of shock, disbelief, anxiety, fear, and despair. Within that moment, research has shown that some parents cannot distinguish between the unconscious wish for an idealized normal child from an unthinkable, sudden reality of one who is not." William, Healy E. 1996. Helping Parents Deal with the Fact That Their Child Has a Disability. *CEC Today*, Vol.3 No. 5.

## 5.5. Financial situation

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Article 28. of the CRPD obligates all member states to recognize and to enable an adequate standard of living for persons with disabilities. That obligation includes nutrition, clothes, place for living and constant improvement of the living standards for every person with disability, without discrimination on the ground of kind or origin of disability. According to the Constitution of BiH, the right of persons with disability to social protection is regulated on the entity level, but on the level of FBiH it is regulated in common jurisdiction of cantons and FBiH. Since 2009, financial support in terms of cash benefits in BiH is available only to the families with children with a disability of 90% or more (the more complex type of disability) which has excluded many persons with disabilities and their families. Parents often complain and demand a revision of the level of disability with the aim to exercise their rights to financial support.<sup>36</sup> This issue in particular affects families with children with intellectual disabilities who don't have physical disability, and who are often assessed to have less than 90% of disability, which results in lack of financial support.<sup>37</sup> Detection of and records on persons with disabilities are not institutionally adequately organized making it difficult to develop programs for persons with disability within social protection. Financial support given for care is often treated as benefits for supporting a person with disability, and not to support their independent living. Family is the base and only service for person with disability because the society didn't develop any mechanisms of support for families and people with disability.<sup>38</sup> Bosnia and Herzegovina spends about 4% of its GDP on financing social support, including persons with disabilities. This is higher than in other European countries (except for Croatia). However, most of these funds are spent for the support to war veterans and families of fallen soldiers (approximately two thirds) leaving very limited funds for all the other users of social protection. This is evident from the fact that social support for persons with disabilities is significantly under the European average and system does not guarantee even the minimal support required.<sup>39</sup>

Evidence of families not being able to provide adequate support to their child with disabilities abound in our research. Sometimes access to an existing service is prevented due to lack of funds for transport as in the case of Aldin whose parents believe doctors in Sarajevo are better experts for his case, but due to their difficult financial situation they cannot take him there all the time so he visits the doctors in Goražde. His parents also fear that he will not be able to continue to secondary education because they will not be able to drive him to the Goražde high school every day. They also said how they

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36 Bećirević and Dowling, 2012: 12.

37 Ibid. p.11.

38 My Right – Empower People with Disability 2011:16.

39 European Union EIDHR Program for Bosnia and Herzegovina 2014. Report on Compliance of Legislative and Institutional Framework in Bosnia and Herzegovina, Serbia and Montenegro with UNCHRDP and Recommendations for Harmonization, p. 67.

have such a bad experience with scholarships, that they have stopped applying because usually those who get a scholarship have lower grades than Aldin. Zorica's father, Obren, also fears that she will not be able to go to high school despite her good grades. He knows that this is what Zorica is most upset and anxious about.

Families of children with disabilities have a higher risk of falling into poverty, in particular in societies such as BiH where services for them are not readily available and parents have to fundraise to ensure their children receive the necessary treatment, medication, rehabilitation or access to education. So many sentences in this study reflect this situation.

"Financial support would be so significant for us." Bojana, mother

"Obstacle [for spa rehabilitation] is funding." Razija, grandmother

"Even her disability benefit was not enough to cover the transport costs for her treatments." Safeta, mother

"[the diagnosis procedure] was so difficult to manage financially. My wife had to leave her job, I find some jobs on and off, and the only regular income is that of the grandmother. We live in rented property." Saša, father

"I do not see a way out unless I get employment. ... I plan to make some savings for her ... 20,000KM in 10 years, but how to do that if I was not able to save more than 100KM last year?" Đina, mother

"Anything at all...agricultural subsidies...material aid, it does not have to be money, for instance donation of cows..." Goran, father

"We lacked funding to pay for 15 days for her to be in swimming pool which would enable her more stability on the ground. We did not get any assistance to go to Fojnica [rehabilitation spa] again. We lost a chance. The doctor said she was on the breakthrough to succeeding, but we did not have the funds. Rare moments when her brain connects to [the nerves in] the legs..." Zdravko, father

All families of children with hearing difficulties spoke about the costs of assistive techniques for their children, the expensive batteries, very expensive service or spare part replacement. "I do not understand that I have to pay for my child's hearing aid. I am employed and I pay social protection taxes, and yet I have to pay for his hearing aid." Dragan, father

Anđela's hearing aid replacement costs are quite expensive, and the cheapest service fee is 120KM, while new batteries are 450KM, and the new magnet even 800KM. Her family is happy that there were no major damages to her hearing aid so far, but also believe that parents of children with cochlear implants should be provided with some subsidies. Dario's parents decided to continue getting him the hearing aid 'Naida 3' as it was advised by doctors in Belgrade. That hearing aid is

much more expensive than the one he would get through the health insurance, and his parents have to top up the price with 1200KM every time his hearing aid is replaced. Like other parents, they too pay for the service for possible damages and for the batteries. Božana had to undergo surgery last year that costs 50,000Euro and in the first instance the parents were told that they would have to fundraise this amount on their own. They even considered not having the surgery, but later managed to get support from the health insurance fund.

Families of children with sight difficulties are also facing high costs of medical treatments, as well as assistive technologies. Mona had three surgeries in Belgrade that cost 5,000Euro each, in addition to the travel and accommodation costs in Belgrade. Some of the costs were covered by the companies where her parents work and the company where her mother works allowed them to use their vehicle and driver for surgeries and control visits. The subsidy for assistive technologies, including glasses is very low, and Senad's family has to pay most of the bill. "There is a lack of literature for blind and visually impaired children, even the library near the Town Hall in Sarajevo is now temporarily closed. A blind student is the most expensive student. The pen with which he learns to write is 800Euro. He needs at least 1,500Euro of assistive technology just to learn to write." Senad's educator

Although there are legal benefits for parents of children with disabilities to request to work part-time and receive full time salaries,<sup>40</sup> in practice this does not work out very well, in particular if existing employment is with private companies. "There is no private company owner who is prepared to understand the problem that we have. ... I had to resign on my own accord, simply because private company owners do not have understanding. On the other hand, I have no other choice, my child is a priority." Zorica, mother

The response from one of the study participants on how much money do they think they had to spent to maintain the support for their child with disabilities, probably sums it up the best: "As my husband says 'We could have purchased a flat in the center of Zagreb.'" Magdalena, mother

Parents of children with disabilities, as well as entire families that have children with disabilities, need to have specific support programs in place that will ensure that they do not face the risk of falling into poverty. There are specific costs that need to be covered by the existing social and health protection services, and new subsidies must be introduced. Harmonization of legislation with the CRPD needs to look into other legislation that is not necessarily immediately associated with disability issues, such as customs and excise, entrepreneurship and agriculture, in order to ensure that families forced to import necessary medication and assistive techniques are exempt from customs taxes, and that programs that target socially excluded groups include not only persons with disabilities but also their families.

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40 In the case of RS.

## 5.6. Ableism and the magic wand

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Stereotypes and prejudices about persons with disabilities are a continuous and common obstacle to their social inclusion. A movement was started that had the aim to address this obstacle from the perspective of persons with disabilities, rather than the perspective of society. The idea is to reverse the approach from a so called disablist approach to an ableist approach because "... the maintenance of a non-disabled identity ... is a more useful problem with which to be concerned; rather than interrogating the other, let us deconstruct the normality-which-is-to-be-assumed."<sup>41</sup> Ableism is defined as "... a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human."<sup>42</sup> Another scholar defines ableism as "ideas, practices, institutions and social relations that presume ablebodiedness, and by so doing, constructs persons with disabilities as marginalized ... and largely invisible 'others.'"<sup>43</sup>

Ableism is reflected in BiH society through prejudices about individuals and groups of persons with disabilities based on their condition, appearance, speech, and behavior. In a newly democratic society like BiH, where government institutions started raising awareness on the rights of individuals with disabilities only in the last decade, such stereotypes and prejudices abound in everyday life: in the park, on the street, on public transport.<sup>44</sup> The stereotypes are also reproduced by the media which continue to present an inadequate (and sometimes negative) approach towards disability issues and often use intimidating or discriminatory terminology. Media in Bosnia and Herzegovina present questions about disability in a very unprofessional way, often as a tragedy or a sensation.<sup>45</sup> Media also put an emphasis on an ableist heroic approach to children with disabilities. The ableist presentation of the heroism of a child with disabilities appears when the success of a person with a disability is reported on only because of the fact that it is a person with a disability, rather than putting the focus on their accomplishment as child that has excelled in a specific area of life.

Although we have seen how parents play the most important role in supporting their children with disabilities in this study, we have come across examples where they, too, fall prey to the traps of ableism. The source of an ableist approach comes from the parents' desire that their children are healthy and well, and perception

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41 Tom Shakespeare in Campbell, Fiona Kumari. 2008:1.

42 Campbell 2001:44.

43 Chouinard 1997:380.

44 My Right – Empower People with Disabilities 2014: 41.

45 Disability Policy in Bosnia and Herzegovina 2008: 4.

that the child's disability is an enemy to the good health and prosperous future of their children. Parents usually find out about their child's diagnosis in a hospital and the medical staff are the first to whom the parents can address their concerns, the first shock of hearing that news. However, medical services and social protection providers in BiH do not offer adequate information about the rights and services that children with intellectual and physical disabilities and their parents are entitled to.<sup>46</sup> Most parents were not given enough information from health care workers about their child's condition/disability, what to expect, how the child will develop. Parents often leave the hospital confused and frightened.<sup>47</sup>

"The first reaction was not accepting the reality. I was fighting with myself and researching ...on the internet, researching about autism and when I discovered he has seven out of the ten characteristic traits of children with autism it was a cause for alarm. I fought myself in an attempt to recognize and accept [the diagnosis] ..." Bojana, mother

"Bojana persuaded me to accept that we have to start doing medical examinations. I must admit that I was the one who was the last to 'find out' what was going on. To be precise: I did not want to see and know what was actually going on [with their children with autism] ..." Zoran, father

This initial rejection of the child's diagnosis of disability also tends to develop into a strenuous search for a 'cure' or for some 'magic wand' that will transform a child with a disability into a non-disabled, typical child. Parents go to great lengths to find adequate treatment, appropriate expertise that might 'heal' their child. This process is very different from the usual quest for adequate health and social services for children with disabilities, as this ableist quest does not have the children's well-being in focus, but it is rather addressing the parents' expectation that the child's condition of disability can be reversed.

"We carried her a lot, I hope she will walk one day, this is how I thought then." Marko, father

"The priority was, for the doctor and for us, that Aldin stands on his own legs and starts walking independently." Halid, father

"Previously, my greatest wish was that she would say 'mother' and that she would recognize that I am her mother." Sanja, mother

Parents go to great lengths in hope to reverse the disability diagnosis, sometimes even acting on their own accord, when medical advice is not available.

"There was no advice. I never went to the Development Counselling [Center]. We went wherever they sent us. For instance, when she was one year old I started

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46 The Institution of Human Rights Ombudsman of Bosnia and Herzegovina. 2010:48.

47 Bećirević and Dowling. 2012:10.

putting her into the walker, in hope that it would strengthen [her legs]. I did this for a few months, but she could not do anything, she could not even push herself for an inch. Then when we came to Slavonski Brod [Development Counselling Center] they [were astonished] when they asked me 'Why are you putting her in the walker!?' Safeta, mother

"After a year and a half the child was supposed to start walking, however, there were no indications this was going to take place. We went to the therapies on a regular basis ... but soon it became clear Lucija will not walk. She is using a wheelchair... We undertook all kinds of treatments because doctors made forecasts that she might start walking when she is three, four, five years old ... but for all that effort this did not happen and we stopped hoping she would ever walk again ..." Slaven, father

Some parents are sensitized enough to recognize service providers who offer false hopes. "There are people who want to abuse someone's torment, those numerous 'magic treatments' like MMS drops, we always kept away from such promises of curing children overnight...one has to be wary...we have been offered all kinds of stupidities, but we managed not to fall prey to them." Zoran, father

The ableist approach of the environment, the social expectation that parents can be happy only if their child is well, healthy and non-disabled, the labelling of children with disabilities as 'family tragedies' can also greatly contribute to the parents' ableist approach.

"My father keeps on saying, oh I wish Andrej would start to speak...he does not understand the substance of the issue...nor does my mother." Bojana, mother

"When we found out about the diagnosis, it was extremely difficult, we even had to comfort our extended family members ... The environment usually reacted with pity." Elvira, mother

"First the grandmothers and grandfathers were saying 'Come on, she will walk one day.' [Then others were saying] 'Come on, you will see, she will start walking, come on.'" Magdalena, mother

"She is a very sick girl and we all help her when she needs it. My dream is that Daja is well. I think that her dreams are that she will recover and that she can walk with us and play." Dragana, friend

Even children with disabilities start hoping that their disability will be reversed and do not embrace disability as part of their identity.

"His greatest wish is to recover, to get well and to be able to walk...He had a dream to go to the *Hajj* and we collected money, the whole school, and we helped him to go there. He thought he would recover there." Mia, friend

The parents have a stake in “creating a more inclusive and tolerant community environment as it would benefit both themselves and their children” and they need to be recognized as “potential allies in the fight against ableism.”<sup>48</sup> However, “often parents are overwhelmed because many feel ill-equipped to deal with the realities of handling the child’s physical, psychological, and/or educational needs”<sup>49</sup> and they need to be supported in this role by medical professionals who are their first point of interaction in the process of getting acquainted with their child’s disability. The means to improve the support health care workers can provide to the parents, in particular during the diagnosis process, and as shared by parents, include better communication and awareness, emphasizing the positive aspects of the child’s diagnosis as well as being sensitive to the parents’ experience.<sup>50</sup> Ableism is a socially created phenomenon that needs to be addressed by those professionals and institutions that are at the forefront of contact with persons with disabilities - the health and social protection, and education sectors. They have a significant role in influencing the general population (and thus are responsible for creating societies sensitive to disability issues or those that are prejudiced), but most importantly influencing the key supporters of children with disabilities - their parents and family. It is therefore necessary that all staff working with children with disabilities and their parents are sensitized and trained to provide holistic support to families of children with disabilities. Policies developed to provide health and social protection, and education to children with disabilities also are obliged to employ a participative approach and include persons with disabilities in both the policy development processes as well as the monitoring of its implementation at all levels of government.

## 5.7. Disabled society

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Barriers that persons with disabilities face, in particular in the tender age when they are still children, are not only physical/architectural obstacles or information inaccessibility, but also attitudinal barriers. Whether born from ignorance, fear, misunderstanding or hate, these attitudes keep people from appreciating and experiencing the full potential a person with a disability can achieve. Persons with disabilities are now asking that the approach is reversed, that their disability is not seen as ‘their fault’ and that equal opportunities should not be only their plight, but that of the society as a whole. The message is that it is not the persons who are disabled, but it is the society that does not have the ability to create equal opportunities for all its citizens. If streets can be accommodated to respond to expanding cars in cities, or new lanes can be made to respond to the needs of bicycle drivers, then it is

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48 Neely-Barnes, S. et al. 2010: 247.

49 Reio and Fornes 2011: 53–61.

50 Bećirević and Dowling 2012: 10.

equally the responsibility to adapt the streets to wheelchair users, persons who use the white cane, or those who need simplified and descriptive information. The idea behind the concept of a disabled society (or the social model of disability) stemmed from the Fundamental Principles of Disability document first published in the mid-1970s<sup>51</sup> which argued that we were not disabled by our impairments but by the disabling barriers we faced in society.<sup>52</sup>

Children with disability are excluded from the society because of the lack of information about disabilities, because of prejudices and fears that prevail in society.<sup>53</sup> The study has evidence to corroborate the existing arguments that there is no encouraging environment for children with disabilities to feel they are included in society.

"I am most upset when I see the way other people look at my children, those who do not know that they have a problem. They are all staring at us, in particular if the boys are upset. We are a primitive society. I recently talked to a mother of an albino girl and she also said that when they go out in the street that everyone stares at them, as if she is I-don't-know-what. ...People are afraid of the unknown, they have this fear until they become familiar with the situation and that is the problem, the lack of knowledge, lack of understanding." Zoran, father

"There were all kinds of stories behind our backs, strange looks, but also support from other people." Almira, mother

Kača's older brother had an unpleasant situation because someone said that his family is "pitiful" because he has a sister with a disability.

There are examples of neighbors or family friends of families with children with disabilities that are good examples of sensitized citizens, who endeavor to make the society we live in less disabled.

"I am amazed with the courage of those women, their strength and optimism. Those parents are the positive source of inspiration for us, who are not faced by such challenges. I feel bad because I cannot help a lot as an individual. ...As a society we must be more engaged, we must be louder, we must initiate some action!" Ivana, neighbor

"We have shared sickness and health for 40 years as neighbors. I know Amin since he was born... [despite his disability] he is clever and intelligent, we talk, he likes talking about the cosmos, religion, he is devoted to faith..." Paša, neighbor

"Society should take more care of children with disabilities, they are often isolated. I heard that there are some associations here, but they are not doing a good job." Boro, neighbor

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51 UPIAS 1976. Fundamental Principles of Disability. London: Union of the Physically Impaired Against Segregation

52 Oliver, M. 2013:1025.

53 Karapuš, B. 2006:7.

"I think it is necessary that people meet children with autism, that they try to talk to them, to spend time with them, because they would change the way they think about them." Aida, neighbor

"The society needs to be educated more, to be informed and recognize that those persons with disabilities also have abilities and that they are not scary, because some people are afraid of them." defectologist, Đ.G

We also came across teachers who are aware that not all children with disabilities have parents who advocate for their rights, but rather that some are embarrassed about their disability and choose to hide it from the neighbors. "The problem is always what will the neighbors think. There are parents who hide the diagnosis because they are afraid of what the neighbors will gossip about their child not being this or that way. It is sad. Many children came to my preschool with evident issues, but the parents wanted to hide this, as if they were embarrassed to have a child with disability. ...Parents are also faced with condemnation from the neighbors, the society has not done anything to accept disability as a normal regular thing, to stop excluding those children." Pre-school teacher

Children with disabilities are aware that they are different and that the society they live in is not taking the necessary steps to include them together with their differences. Amin, six years old, for instance, who is devoted to his faith, cannot visit the mosque whenever he wants because of the architectural barriers of the mosque. So, he goes there only on rare occasions. Although Dajana, 11, gets along with all her classmates, sometimes they tease her, and she does not like that. "I went to a birthday party last week and it was great. I liked it. My class was there. We played together. I took my dog with me. The children know that I am different. They help me learn and they are good towards me. I don't think I am different." Dajana, 11 years

"I often go to my grandmother's. It is the only place where I go. She lives near the church in Tomislavgrad." Višnja, 15

Examples of social exclusion and the disability of society are abundant in every aspect of life. Given that there is no elevator in the building where Dajana lives, her father carries her to the third floor every day, more than once. He also sometimes carries her to the school, or drives her on a bicycle or sled. As she has started gaining weight from the anti-epileptic medication, this is an even bigger physical burden for her father. "For instance, the pavement is accessible on one side, but not on the other side [making it impossible to cross]. I can still carry her. We have a wheelchair that will not fold, so I have to return it [home after use] because we cannot fold it when we want to enter a bus..." Zdravko, father

"They bombard us with jumbo posters about the rights of persons with disabilities but when you go, I don't know, anywhere, to the municipality, there are five or six flights of stairs and you are powerless when you are with your child who is a

wheelchair user. Hardly any of the public buildings we are expected to use are accessible." Slaven, father

One mother was even confronted by a medical worker. She says how the family learned how to cope well in general with her daughter's diagnosis "My husband, and sons, and I, we were happy, but usually the reactions were 'Why did she need this?' even a doctor said 'Help us dear God, you did not have to give birth to her!'" (Đina, mother)

In such a discouraging environment, it is no surprise that the parents and friends lose a lot of energy worrying about the future of their children, in particular once the parents are gone. "I am most concerned about her when she grows up. She is female. I don't know how she will react to all of that [growing up]." Branka, mother

"What will be of her in the future? Who will take care of her? Everything is well while the parents are alive..." Radojka, neighbor

There are good examples of parents being able to integrate their child with disability in all family activities, getting support for what they do and for their child. They act not only on behalf of their children, as those who force their children into social inclusion, but also as those who force a disabled society into becoming an inclusive society. "When I think of our environment, we really had support from everyone. When Dario started school, we invited everyone over for lunch and thanked them for the patience they had with us, and our need to only to talk about Dario. ...We had support from everyone: our neighbors, family, other people who understood us." Slađana, mother

"When we first met Višnja she was little and her parents took her around in a pram, and I did not understand what was wrong with her. I was afraid because I did not know how to approach her, I did not want to hurt her. But when I saw how her parents dealt with her, I became relaxed. Višnja goes everywhere with her parents, and we are beyond the times when children with disabilities were kept hidden away." Josipa, neighbor

"I take her everywhere with me. Many people know her in town. She is communicative and a positive person. She does not consider herself a child with disability and that is how she behaves." Milorad, father

A disabled society has the potential of becoming an inclusive one, once it recognizes the potential of children with disabilities, recognizes their abilities and has faith in their capacity to become much more than what might seem possible at a given moment. "Božana will be a director of a successful company one day, and if I have to give a mark of one-to-ten she gets 11 from me. She is communicative and clever, she has above average intellectual abilities, and for the lack of hearing - the way we hear - she has already compensated that. She can be whatever she wishes to be." Mirela, speech therapist

Unfortunately, the prejudices from the disabled society have resulted in the fact that these children are usually isolated, without possibilities for socialization and achieving their essential rights.<sup>54</sup> It is necessary to take steps to raise the awareness in the society so that children with disability can be involved in society just like any other child. This necessity is not the obligation of the children with disabilities, their parents, families, associations, it is the duty and obligation first and foremost of the BiH government authorities that have committed themselves to ensuring an inclusive society and enabling and encouraging environment, but, secondly, it is also the moral duty of every single citizen of BiH - the children's neighbor, classmate, doctor and passer-by.

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54 The Institution of the Human Rights Ombudsman of Bosnia and Herzegovina 2010:5.

# 6. Recommendations

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The following recommendations are based on the findings of this research, as well as existing key studies and reports on disability issues in BiH. The recommendations are divided with regard to the different groups of report readers and public.

## 6.1. Government authorities at all levels

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### Education

Education will be accessible for children with disabilities, once the government authorities in BiH start creating mechanisms for the implementation of inclusive education that is already enshrined in the BiH legal framework. These implementation mechanisms need to be supported with the development and provision of:

- The understanding that inclusive education is a compound education system that includes, and is not limited to: schools that are accessible both in terms of architectural barriers and information accessibility, school management that is trained, sensitized and dedicated to including children with disabilities into mainstream schools; teaching staff trained in inclusive education and sensitized to disability issues; ongoing support to teaching staff both in terms of supervision and practical curricula implementation; teaching assistants who are trained in inclusive education; continuous support to teaching assistants in order to enhance their work with teachers, classmates, classmates' parents in providing adequate assistance for the education of children with disabilities; development of individual programs (prior to start of school year); a student support plan, that may include: physical, emotional, and sensory supports; adapted materials; assistive technology; personalized performance demonstrations; personalized instruction; and individualized grading and evaluation plans; family-school partnerships.

- adequate budgetary allowances for the implementation of inclusive education, for pre-school, primary and secondary schools, university and life-long learning, at local, cantonal (FBiH) and entity levels;
- inclusive education working groups established at local level to include representatives from municipalities, schools, social protection services, support professionals (speech therapists, defectologists, personal assistants, psychologists), NGOs, and parents of children with different areas of disability;
- Regular research on children and youth with disabilities and their families conducted;
- Statistical data on children with disabilities compiled as part of ongoing education data collection;

## Access to services

Children with disabilities need continuous access to quality services that will be provided by highly skilled and qualified staff in institutions that are free and accessible. Governments at all levels need to develop and fund programs for the provision of:

- social protection services,
- health services,
- assistive technologies,
- specialized services, and
- continuous education, training and sensitization of staff working with children with disabilities.

Parents of children with disabilities need to be supported in parenting and in some cases caring for their children with disabilities through the continuous provision of:

- psycho-social support and treatment during and after the diagnosis process,
- inclusion in the development and implementation of education programs,
- support groups in schools, medical and rehabilitation institutions with other parents of children with disabilities,

- access to parent-teacher partnership programs, and
- access to income-generating opportunities.

Finally, it is important to ensure that all services are accessible to all children with disabilities and their parents, as part of mainstream service providing locations, and only when it is necessary develop “special services” for children with disabilities.

## **Access to health protection and insurance**

Health institutions, professionals and services they provide require to develop and ensure funding for programs that will:

- ensure that health protection and insurance are accessible to all children with disabilities,
- train and sensitize all medical and support staff in disability issues, ensuring the ableism trap is avoided,
- develop cross-sectoral early identification of disability programs for children,
- ensure physical and informational accessibility to children with disabilities,
- create child and disability-friendly environments,
- ensure necessary and adequate equipment and medication to respond to the specific needs of children with disabilities, and
- create “one-stop-shop” centers where the entire diagnosis procedures can take place and be completed.

## **Support to families of children with disabilities**

Parents of children with disabilities, as well as entire families that have children with disabilities, need to have specific support programs in place that will ensure that they do not face the risk of falling into poverty. There are specific costs that need to be covered by the existing social and health protection services, and new subsidies must be introduced. Harmonization of legislation with the CRPD needs to look into other legislation that is not necessarily immediately associated with disability issues, such as customs and excise, entrepreneurship and agriculture, in order to ensure that families forced to import necessary medication and assistive techniques are

exempt from customs taxes, and that programs that target socially excluded groups include not only persons with disabilities but also their families.

## Awareness raising

Unfortunately, the prejudices about the disabled society have as a result that children with disabilities are usually isolated, without possibilities for socialization and achieving their essential rights. It is necessary to take steps to raise the awareness in the society so that children with disability can be involved in society just like any other child. This necessity is not the obligation of the children with disabilities, their parents, families, associations, but it is the duty and obligation first and foremost of the BiH government authorities that have committed themselves to ensuring an inclusive society and enabling and encouraging environment, but secondly, it is also the moral duty of every single citizen of BiH, the children's neighbor, classmate, doctor and passer-by. In order to prepare and plan awareness raising steps it is of crucial importance to have statistical data on children with disabilities, disaggregated by sex, age and other variables. This data need to be part of a regularly updated "registry" of persons with disabilities that will ensure different sectors can create plans and programs to support children with disabilities and enable them and their families to enjoy their rights.

## 6.2. Non-government organisations

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The NGO sector, both disabled persons' organizations as well as other NGOs, should direct their efforts towards programs that will provide services for children with disabilities, which government institutions are not (yet) providing. The NGO sector should not replace the government obligations to provide these services, but it should rather serve as an example of how these services can be provided in a highly qualified, good quality and participative manner. These programs should be co-funded by government authorities and their handing-over to public institutions programs foreseen from the very outset.

Although the NGO sector cannot and should not replace some public institutions and their services, the flexibility of NGOs can be utilized to introduce some improvements at a quicker pace. For instance, schools in some areas of BiH can request personal assistants for the children with disabilities they enrolled from ministries of education, but the ministries do not have access to an existing pool of personal assistance, nor do they have the capacity and flexibility to identify, train and employ assistants at a short notice (e.g. between May when children are enrolled and September when school starts).

Even when NGOs are providing services for children with disabilities and their parents through periodic projects and without continuity, these services still need to be clearly defined, standardized and certified in a way that the services provided achieve desired quality.

Organizations of persons with disabilities need to dedicate programs and activities in order to increase awareness in the general public about children with disabilities. Advocacy programs for policy and legal framework changes, that lobby for the implementation of CRPD cannot be initiated nor implemented without equal participation of the representatives of disabled persons' organizations and representatives of organizations of parents of children with disabilities.

## **6.3. Parents of children with disabilities**

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The parents have a stake in ensuring their children with disabilities have the freedom and flexibility to be independent members of the society. The parents' protective and cradling approach can stunt the child's development and independence, and the parents need to check their attitudes and behavior continuously. The parents' approach towards their child with disability reflects on the community environment and can steer it, on one hand, to perceive the child only through its lack of ability and capacities and to thus exclude the child. On the other hand, their approach can emphasize the abilities and potential for growth of their child that could create a response in a more inclusive and tolerant community environment. Parents, of course, need to be supported in this process, through individual and group workshops, guidance and opportunities that would ensure they are not overwhelmed by the fear of falling into poverty.

# About the Author

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Lejla Somun-Krupalija works as a researcher and policy developer in the field of social inclusion, in particular persons with disabilities and gender equality. Her interdisciplinary education extends from a graduate degree in Arabic language and Philosophy from Sarajevo to a postgraduate degree in Forced Migration from Oxford. In late 1980s she started working with the United Nations and continued as a trainer and manager in the non-government sector and an elected official in local government. Lejla implemented projects on capacity building of government institutions and non-government organisations, integration of a human-rights based approach. She lead the project that developed the Disability Policy for Bosnia and Herzegovina 2006-09, and was the rapporteur for the First Alternative Report of Bosnia and Herzegovina on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014. She is a feminist and a parent of a young woman with autism.

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