An analysis

of current and possible future models for supporting people with disabilities in Bosnia and Herzegovina



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EMPOWERS PEOPLE WITH DISABILITIES

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Introduction

For approximately 40 years, there has been an increasing focus in society on people with disabilities, as reflected in their changing status in the community and changing attitudes to their rights and needs.

A number of levels can be identified in society's response to calls by people with disabilities for recognition and acceptance as equal members of the community:

- At the international level, a number of documents oblige governments to
 ensure their human rights and social inclusion on an equal basis, as well as to
 monitor the degree to which adopted standards are implemented. The most
 significant are the UN Standard Rules on the Equalization of Opportunities for
 Persons with Disabilities (1993) and the Convention on the Rights of Persons
 with Disabilities (2006), on the back of which regional and national disability
 action plans have been developed.
- At the European level (Council of Europe and European Union), documents have been adopted that set out the policy framework, standards and obligations agreed to by member states, including the Council of Europe's Action Plan and the EU Strategy on the Equalization of Opportunities for Persons with Disabilities 2010-2020.
- At the national level, governments have subscribed to international standards on disability, with promises to develop mechanisms that put them into practice. Strategy documents are in development to determine key areas of government intervention and improve the status of persons with disabilities.
- At the local level, action plans for international and national standards are being developed. They outline actions that will impact concrete areas of interest to individuals with disability and directly result in overhauling their rights and degree of social inclusion.

This whole process with regard to society's treatment of persons with disabilities is taking place in a context of change and transition from "charitable" and "medical" models to a "social" one based on full respect for their human rights and creating the conditions for equal opportunity.

Ratification by Bosnia and Herzegovina of the *Convention on the Rights of Persons with Disabilities* in 2009, following the adoption in 2008 of the Common Disability Policy and the entity disability policy implementation strategies, marked the achievement amongst social stakeholders interested in disability issues of a

consensus on developing mixed models of support, including various forms of financial assistance and the system of services needed, based on a thorough review of the rights and social inclusion of persons with disabilities in community life.

Given the international, national and local documents which define the framework for developing new models of support for persons with disabilities, the authors of this report have identified and analyzed existing services available to them, provided at various levels of government by public institutions, nongovernmental organizations (NGOs) and organizations of persons with disabilities (DPOs).

This report covers the areas of service provision that have the greatest direct impact on the full enjoyment of their human rights and dignity, equalization of opportunities, social inclusion and development of life potential by persons with disabilities.

It represents a contribution to a better understanding of existing models of support and the need for new ones based on individuals' actual needs and developed at community level, facilitating full participation and the full development of their potential by persons with disabilities.

The report's aim is to empower different stakeholders interested in changing society's approach towards persons with disabilities and to encourage partnership action so as to establish new support modalities.

It is hoped that it will provide advocates and other stakeholders with the necessary information on models of support available under the current system, as well as helping them launch effective advocacy processes for the establishment of new, widely acceptable, but targeted services for individuals with disabilities.

The report is also intended as a contribution to the reform process and the implementation of international standards, the national and entity strategies, local action plans and laws and regulations, resulting in the development of a wide range of community-level services for persons with disabilities.

Finally, the report is intended as a contribution to the further development of partnership between relevant decision-makers and DPOs that is fully inclusive of individuals with disabilities in the processes of development, use and quality assessment of each service.

1. Existing services for persons with disabilities

The dominant model for relating to persons with disabilities in Bosnia and Herzegovina is a medical one. It lacks an appropriately developed system of services for them.

Key features of existing services are:

- The framework under which they have been developed is based on a "charitable" and "medical" model of disability.
- Services have been developed solely on the basis of expert assessment and decisions made by government representatives, with no room for DPOs or individuals with disabilities to affect decisions made.
- In most cases, services are not recognized as exclusively for persons with disabilities. This is particularly evident with health care services.
- Even when services for persons with disabilities do exist, they are often inaccessible to some due to inadequate or inconsistent application of standards.
- Where service providers are NGOs or DPOs, services rarely cover all persons with disabilities in the area of service delivery.
- Given that services provided by NGOs and DPOs are based on donor funding through projects, services are time-limited and unsustainable over the longer term.
- Existing services have been designed to meet general assessments and do not take into account the specific needs of individuals.
- Any new support model that includes introducing services in a range of areas
 faces resistance from many individuals with disabilities, normally because the
 opponents do not need the services in question. A model based on cash
 allowances is desirable, as certain funds for support function as a monthly
 income supplement.
- Governmental institutions also contribute to resistance to change by generally
 viewing reform processes in terms of budget savings and so as largely based
 on administrative reforms, with a negative impact on those with the most
 severe disabilities and the greatest need for a range of support to their day-today functioning.

Current conditions have reduced very many individuals with disabilities who require support services to extreme poverty and placed additional burden on their families, while preventing them from participating actively in private and public life and radically increasing their social exclusion.

This report presents an analysis of available services in education, health care, social protection, labour, employment, vocational rehabilitation, independent living, social and supported housing, culture, art and public information.

Currently, services are provided by public institutions established by government at various levels, nongovernmental and humanitarian organizations and organizations of persons with disabilities.

1.1. Education

In ratifying the *Convention on the Rights of Persons with Disabilities* and opting for accession to the European Union, Bosnia and Herzegovina has made a commitment to pursue the highest standards in access to programs for education and upbringing of persons with disabilities, including inclusion in mainstream programs, individualization of programs, providing appropriate support in human and technical terms, providing information and making environments accessible.

Given the political structure of Bosnia and Herzegovina and the distribution of responsibilities between state and entities and, in the Federation, between entity and cantons, it can be very difficult and even impossible to ensure that persons with disabilities have equal opportunity of access to educational programs throughout the country.

Existing regulations clearly prohibit any form of discrimination on the basis of disability, emphasizing every child's right to education under equal conditions. Nonetheless, difficulties children and young people with disabilities experience in exercising this right include inadequate spatial and material conditions, inaccessible public transport, environmental and architectural barriers to their movement and their access to information, uneven distribution of institutions, lack of qualified personnel, prejudice, inaccessible textbooks, literature and didactic aids. Few educational institutions plan the resources needed for inclusive education programs for children and young people with disabilities. Teacher training does not include modules to prepare them for working with children and young people with disabilities. Inaccessible and inappropriate education thus excludes most people

with disabilities, diminishing or preventing their development and training for life and work.

There is a system of special schools which a smaller number of children and young people with disabilities attend, but their institutional status has not been fully settled and few have appropriate conditions. There are special public educational institutions for people with impaired sight, impaired hearing, intellectual disabilities or physical disabilities.

Educational services for individuals with disabilities are thus currently provided by mainstream educational institutions, special educational institutions, NGOs and DPOs.

A few "mainstream" institutions, mainly primary schools, have professional teams to support children with disabilities included in mainstream educational programs and their teachers. Such teams generally provide support for several educational institutions, the main form being support for teachers in adapting curricula and working with students with disabilities during the teaching process. Only rarely do they work with parents and peers. For the sake of illustration, a list of typical examples of their work follows:

- In the Republika Srpska, 40 teams provide support to inclusive education in some 260 primary schools.
- In Tuzla Canton, a nongovernmental organization "Duga" has established support teams serving 15 out of 96 primary schools.
- In Sarajevo Canton, support for inclusive education is provided by NGOs and DPOs through a number of projects, with only partial support provided by special education schools.
- As of a year ago, the support teams in Herzegovina-Neretva Canton have not been operational, due to a change in the management of the special education institutions they operated out of.

As these examples suggest, the services needed by participants for their education and upbringing are not being provided in sufficient quantity or quality and the inclusive educational process has been reduced to a mere form, advocated only rhetorically.

Most services provided within special educational institutions are designed specifically for the children and young people being educated in them. Examples include: additional educational programs (training in daily life skills, mobility courses

for the visually impaired, computer training, adapting and printing textbooks). Services in institutions for children and young people with impaired hearing provide translation into sign language, but generally only as part of supporting the formal learning process.

In some special educational institutions, work with parents is facilitated, but mainly as part of projects and so for a limited duration.

Special public educational institutions for persons with intellectual disabilities include:

- 1. The "Mjedenica" Institute for the special education and upbringing of children
- 2. The PA Centre for the upbringing, education, vocational training and employment of mentally retarded children, children suffering from autism and cerebral palsy at the "Vladimir Nazor" school for secondary vocational education and training, Sarajevo
- 3. The Special Primary School, Zenica
- 4. The Special Secondary School, Zenica
- 5. The PA Institute for upbringing and education of persons with disorders in mental and physical development, Tuzla
- 6. The "Sulejman Omerović CAR" Special Primary School, Maglaj
- 7. The Primary School for Children with Special Needs, Mostar
- 8. The "Đorđe Natošević" Primary and Secondary Schools for Children with Emotional Disabilities, Prijedor

A number of other centres also provide, amongst their other activities, limited forms of education for persons with intellectual disabilities:

- 1. The Day Centre "Duga", Novi Travnik
- 2. The Rehabilitation Centre "Sveta Obitelj", Mostar
- The "Los Rosales" Centre for Children and Young People with Special Needs, Mostar
- 4. The Home for Children with Physical or Intellectual Disabilities "Marija-naša nada", Široki Brijeg
- 5. The Centre "Zaštiti me" in Banja Luka, with both a primary and secondary school

Public educational institutions specifically for blind people are the Centre for the Education and Upbringing of Blind Children (a primary and secondary school) in Sarajevo and the Institute for Blind Children "Budućnost" (a primary and secondary school) in Derventa.

The special public educational institutions for persons with impaired hearing are the Sarajevo Centre for Speech and Hearing Rehabilitation, the Tuzla Centre for Hearing and Speech Rehabilitation, and the Banja Luka Institute for the Education and Upbringing of Children with Impaired Hearing.

The services provided within such institutions are closely tied to the conduct of the educational process.

Organizations of persons with disabilities have no impact on the educational system or designing and supervising services in these institutions. As a result, individuals with disabilities who are educated in this way do not acquire the skills to apply in everyday life. The knowledge acquired in occupational training is also inadequate, with resultant exclusion from the labour market.

NGOs and, especially, DPOs do, however, play an important role in supporting the education of individuals, especially when it comes to lifelong learning. This support is realized through projects which are time-limited, of limited geographical coverage and include relatively few individuals or through various forms of training and support, primarily to acquire the knowledge and skills needed to facilitate individual functioning. Some DPOs also provide accessible transportation to educational institutions. Examples include:

- Banja Luka: HO "Partner", the Society of Blind Persons of the RS
- Bugojno: "Leptir", an association of parents, citizens and friends to help children and young people with special needs
- Doboj: The Doboj Region Association of Persons with Paraplegia, Infantile Paralysis and other Physical Disabilities
- Konjic: "I", a citizens association to help children with special needs
- Mostar: "Sunce", an association of citizens, parents and friends of persons with special needs
- Sarajevo: "Oaza", an association to support persons with intellectual disabilities in the Sarajevo Canton area, the Association of Citizens with

Cerebral Palsy, the Sarajevo Canton Association of Blind Persons, the "Life with Down Syndrome" association, the association "Duga"

- Trebinje: The association "Sunce nam je zajedničko"
- Tuzla: The Centre for Children with Multiple Disabilities "Koraci nade"; the Information Centre for Persons with Disabilities "Lotos", the association "Majke hendikepirane djeca"

Clearly these and similar organizations make a significant contribution to the education of persons with disabilities, but the services they deliver are time-limited, of uneven standard, and do not reach everyone who needs them.

Creating equal conditions and an accessible and fully inclusive environment for persons with disabilities in education require work to develop the following services:

- Providing the services of personal assistants in line with their needs for all children and young people with disabilities being educated;
- Accessible transportation services;
- Services to provide assistive devices, with training in their use, repair and maintenance;
- Teachers' assistants;
- Mobile multi-disciplinary support teams;
- Teaching life skills to facilitate full and equal participation in education and society;
- Further education of teaching staff, including the hiring and training of teachers who are themselves persons with disabilities;
- Access to assistive devices and to literature in accessible formats (Braille, sign language, sound technology, large print, accessible content) for all levels of education, interpreters of sign language and other forms of nonverbal communication, and other forms of support to the education of persons with disabilities;
- Support services for parents, especially those whose children are with severe and multiple disabilities;
- Lifelong learning and retraining services for persons with disabilities.

1.2. Health care

The Convention on the Rights of Persons with Disabilities (Article 25) stipulates that signatory states will recognize that all persons with disabilities are entitled to the highest attainable standard of health without discrimination on the basis of disability and take all appropriate measures to ensure access to gender-sensitive health and rehabilitation services.

Under the Constitution of Bosnia and Herzegovina, health care and health insurance are the responsibility of the entities. In the Federation of Bosnia and Herzegovina, the responsibility is shared by the Entity and the cantons.

This decentralization of health insurance and health care, particularly in the Federation of Bosnia and Herzegovina, and the difference in economic power between the entities and the cantons mean that insured individuals neither enjoy equal rights under their compulsory health insurance nor have equal access to all levels of health care and related institutions.

For persons with disabilities, the exercise of their right to health care is marked by discrimination due to the cause of their disability, an inadequate health care financing system, irrational allocation of resources across the levels of health care, an inadequate degree of organization and outfitting of health care institutions, poor accessibility, inappropriate training of medical and paramedical staff, lack of quality control of healthcare service delivery and control of spending.

Access to health care services is unequal, both at primary level (rural vs. urban and between the entities and the cantons) and for more specialized and complex services. Persons with disabilities cannot exercise their right to healthcare if they are not insured. In most Cantons, they cannot be insured on the basis of their disability alone, so that a large number remains without health insurance and care or any way to avail of health care services, resulting in further threats to their health and increasing their degree of disability.

Medical rehabilitation is only partially accessible or adapted for persons with disabilities, and even that only in urban areas. Most existing medical rehabilitation institutions are poorly equipped and employ personnel with insufficient training with regard to their specific needs. Primary medical rehabilitation services are intended for the general population, so that specific areas of rehabilitation needed by persons with disabilities tend to be neglected.

Secondary medical rehabilitation services are not available to all persons with disabilities, as only disabled war veterans are entitled to them under the Law on the

Basic Rights of Disabled War Veterans and other laws related to disabled war veterans' entitlements.

There are no developed early intervention programs or multidisciplinary teams to monitor and support children with disabilities, parents, or similar institutions.

Persons with disabilities are often excluded from mainstream health care services and systematically directed towards specialized medical institutions. On a more positive note, there are 60 community-based centres in Bosnia and Herzegovina within the primary health care system in which people with disabilities can access some medical services and rehabilitation care. They were opened between 1997 and 2004, with 38 in the Federation of Bosnia and Herzegovina and 22 in the Republika Srpska. The aim of this integrated rehabilitation model is to ensure safe and improved access to medical care for persons with disabilities, with an interdisciplinary approach and referral to relevant institutions as needed.

Mental health services are provided through a network of 55 mental health centres, 38 in the Federation of Bosnia and Herzegovina, 16 in the Republika Srpska and one in Brčko District.

Health care services provided by public health institutions, private medical clinics and NGOs and DPOs through projects also offer specific forms of medical rehabilitation, including physiotherapy and psychosocial support for persons with disabilities and family members.

Achieving the highest attainable standard of health without disability-based discrimination means:

- Ensuring all persons with severe and multiple disabilities have a right to health insurance and health care without disability-based discrimination or discrimination based on the cause of the disability;
- Taking all appropriate measures to ensure access to health care services and medical rehabilitation for all groups of persons with disabilities, particularly those with multiple disabilities, women and girls, children and seniors;
- Developing a range of medical rehabilitation accessible to all persons with disabilities;
- Developing programs and measures to promote the prevention of disability;
- Developing early intervention and support programs and monitoring of children with disabilities based on the multidisciplinary approach;

- Providing persons with disabilities with a right to free, individually-adjusted assistive devices, which may to some degree compensate or replace lost or damaged body parts, organs and senses, and enable full or maximum possible independence in performing daily activities;
- Developing a system of services to support the acquisition and maintenance of and training to use low vision, orthopaedic and other assistive devices.

1.3. Social protection

The Convention on the Rights of Persons with Disabilities (Article 28) stipulates that all states recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, as well as continuous improvement of life conditions. It also says that states shall undertake all appropriate measures to protect and promote the achievement of this right without disability-based discrimination.

States should also recognize the right of persons with disabilities to social protection without disability-based discrimination and take appropriate measures to protect and promote their attainment of it, including ensuring access to appropriate and financially affordable services, devices, and other forms of assistance related to needs arising from disability.

Under the Constitution of Bosnia and Herzegovina, social protection is in the sole jurisdiction of the entities. In the Federation of Bosnia and Herzegovina jurisdiction is, however, shared between the Entity and the cantons. This structure of jurisdiction substantially complicates the creation of a unified approach to social protection, especially in providing different forms of support to people with disabilities.

Social protection for persons with disabilities is dominated by measures related to financial support and institutional care, while social services departments are underdeveloped, disorganized and focused on projects. In many cases, existing staff and institutional mechanisms are inadequate to the needs, showing a tendency to stereotype and a lack of openness to new approaches. This field is organized on the basis of entitlements and statuses not individual needs. The approach is based on a system of categories of persons with disabilities. Data and records are not adequately regulated at the institutional level so that no social protection programs can be planned for many with disabilities. Financial benefits are insufficient in scope for the real needs of persons with disabilities and their families. Cash benefits for

care and assistance are often treated as general income rather than as support for independent functioning. Family is a fundamental and in many cases the only support service for persons with disabilities, since society has failed to develop support mechanisms for either the family or individuals with disabilities themselves. The tools and equipment, interpretation services, care and aid, assistance, assistive devices available for persons with disabilities are limited and they must themselves contribute significantly to the cost of providing and purchasing them. Alternative forms of care in the community are underdeveloped and where they exist are of limited capacity and coverage.

There is no single accepted definition of disability and persons with disabilities.

Assessment of degree of disability is not conducted uniformly and is based on the medical model alone, without applying the international classification on functioning as defined by the World Health Organization.

Records and data for persons with disabilities are not processed according to common standards and are incomplete, rendering effective usage and analysis difficult. Various projects in Bosnia and Herzegovina have organized studies on small–scale samples of persons with disabilities, finding that their position and status in society is unsatisfactory.

The system ensuring social security does not have the capacity to meet needs or guarantee a living income and is closely dependent on the financial capacity of the wider system within which it has been realized. There is no state or entity social security system policy. Approaches in different sectors are not harmonized and there is disability-based discrimination in guaranteeing social security. Spending on social security measures related to disability in Bosnia and Herzegovina is significantly below the European or regional average, while spending on disability-related veterans' protection represents two thirds of the overall social allocation. Protection for children with disabilities and their families has not been set at an adequate level and does not cover all aspects of child- and other care, especially in the Federation of Bosnia and Herzegovina. Some rights regarding pensions and disability insurance have been "displaced" into the social protection system, resulting in a significantly worse situation for persons with disabilities.

The working of the support services and social services generally is not regulated by special legislation. The existing law on social protection in the Republika Srpska recognizes the effectiveness of social services and the performance of support services. This area has been developing over recent years, primarily through projects initiated by persons with disabilities themselves and their organizations.

Few support services have been institutionalized, however, and most lack steady sources of support, limiting their impact. The most widespread service in the Republika Srpska is the daily care centres for persons with intellectual disabilities, which have been intensively established over the past 5 years. The traditional opinion is that the family should be solely responsible for caring for persons with disabilities and care is limited to meeting their basic living needs. The produces the *apriori* attitude that additional service departments and services themselves are an expensive luxury.

Local community disability action plans in Bosnia and Herzegovina

Both entities have adopted disability strategies (the Strategy on Equalizing Opportunities for Persons with Disabilities in the Federation of Bosnia and Herzegovina 2011-2015 and the Strategy on Improving Social Status of Persons with Disabilities in the Republika Srpska 2010-2015). Due to Bosnia and Herzegovina's specific political structure, the decision was made to create local disability action plans(LDAP) so that local communities (municipalities and cantons) could create and adopt documents committing them to implement government obligations. Programs attended by organizations of persons with disabilities from the Mostar, Sarajevo, Tuzla, Banjaluka and Zenica regions provided training on drafting local action plans and draft plans were produced for Doboj, Bjeljina, Sarajevo and later Mostar. It is expected these plans will be adopted and implemented by the local authorities. The local disability action plans in Derventa, Doboj and Doboj Jug are integral elements of the municipalities' Strategic Plan for Economic Development. Individuals with disabilities must exert greater pressure on local governance to ensure the LDAPs are implemented in the communities that have adopted them, as well as to prepare similar plans in other municipalities and ensure their adoption by local government throughout the country.

Existing institutions are limited in the performance of their actions and lack any focus on providing the services in the community required to humanize the concept of "social service delivery." For social services to function properly, additional resources must be provided and additional knowledge acquired by professional staff, based on acceptance of the social model and respect for the human rights of persons with disabilities. These are in any case preconditions for a system that facilitates application of the social model of disability. Services may be provided by social institutions, religious or nongovernmental organizations and social enterprises.

The *Law on Basic Social Protection, Protection of Civilian Victims of War and of Families with Children* in the Federation of Bosnia and Herzegovina provides for three entitlements in the form of direct cash benefits to persons with 90% disability or more: a personal disability allowance, an allowance for care and assistance by another person and an orthopaedic supplement. These entitlements are universal throughout the Federation and funded from the Federal budget. The one exception is the allowance for care and assistance by another person for those whose disabilities came about after their 65th year of age. Their entitlement to the allowance is supposed to be covered under cantonal law, but has to date been provided for only in Sarajevo and Tuzla Cantons by legislative amendments.

This entitlement is also not applicable to persons with disabilities living in social protection or educational institutions where a comparable service is being provided for them.

A further entitlement is social benefit, as provided to other citizens, and it can be, e.g. in Sarajevo Canton, 30% higher for persons with disabilities. In some cantons, however, this benefit is not provided at all, as provision is made differently for persons with disabilities.

The **Federal Law on Social Protection** (article 12)defines the beneficiaries of social protection, including those with disabilities and specifically those with physical or intellectual disabilities.

Individuals with disabilities have the following rights: personal disability allowance, allowance for care and assistance by another person, orthopaedic supplies, compensation for expenses related to treatment and purchasing orthopaedic supplies, job training (vocational rehabilitation, retraining and additional training), and employment assistance, provided in the form of financial and other material aid, life skills training, accommodation with a host family, accommodation in social care institutions, social work and other professional services, home care and assistance at home.

There are six categories of civilian victims of war who are also persons with disabilities. Their entitlements include the personal disability allowance or monthly cash benefit, the allowance for care and assistance by another person, the orthopaedic supplement, a family disability allowance, compensation for expenses related to treatment and purchasing orthopaedic supplies, and job training (vocational rehabilitation, retraining and additional training). These allowances are calculated using 70% of the base applied for veterans. Seventy percent of the funds come from the federal, 30% from the cantonal budget.

Civilian victims of war with disabilities have other rights, which are calculated in a similar manner as the personal disability allowance, but with 50% coming from the federal and 20% from the cantonal budget.

The Republika Srpska's Law on Social Protection (an amendment to which is currently in parliamentary procedure) stipulates an entitlement to an allowance for assistance and care by another person for those with severe physical or sensory disabilities, those with developmental disabilities related to more serious and severe impairments, those with multiple developmental disabilities related to moderately serious and severe intellectual disorders, persons with autism and persons with chronic intellectual disabilities and no capacity for employment, with absolutely reduced mobility or unable to meet their fundamental needs without another person's care and assistance, with the proviso that they must be not be eligible for this entitlement on any other legal basis or for accommodation in social care institutions. The same law sets the allowance at 41.00 KM.

Social care services are to be provided by social work centres, social care institutes, and day centres for persons with disabilities, counselling centres, civil society organizations and organizations of persons with disabilities.

RECOMMENDATIONS:

Ensuring the human dignity and social protection of persons with disabilities and their families and mitigating the negative consequences of disability require:

- A social security system accessible to everyone with disabilities that provides them with the necessary forms of support, while encouraging the use of their remaining work and other skills, without excluding or discriminating;
- Reform of pensions and disability insurance so as to include the rights of persons with disabilities on the basis of their disability;
- Ensuring that disability-related expenses do not overburden individuals with disabilities or their families and carers;
- Developing a system of mixed and multidisciplinary locally-based age and gender sensitive social services, tailored to meet the specific needs of persons with disabilities;
- Creating conditions for deinstitutionalization of the support system for persons with disabilities through community-based support services;

- Ensuring that the only special social protection rights persons with disabilities have are specifically related to their disability, while all other social protection rights are accessed in the same way and places as other citizens;
- Including persons with disabilities in all social policy planning processes and in developing and monitoring the realization of social protection programs;
- Ensuring support services for persons with disabilities are affordable and accessible in organizational, architectural, informational and programmatic terms, regardless of age and gender;
- Developing services in the local community with individualized plans that encourage activity and support the independence of persons with disabilities across the board, including independent living;
- Giving persons with disabilities choice as to how services are delivered, as well as of service provider;
- Providing persons with disabilities with access to public services on equal terms.

1.4. Rehabilitation and employment

Under articles 26 and 27 of the *Convention of the Rights of Persons with Disabilities*, signatories are required to take effective and appropriate measures to facilitate persons with disabilities in achieving maximum independence, full physical, mental, social and professional capacity and full inclusion and participation in all aspects of life. To this end, they are expected to organize, strengthen and extend habilitation and rehabilitation services, particularly in relation to health care, employment, education and social services.

In Bosnia and Herzegovina, rehabilitation and employment are under entity jurisdiction, while in the Federation of Bosnia and Herzegovina jurisdiction is shared with the cantons.

The education, vocational rehabilitation and employment processes for persons with disabilities in the Republika Srpska and the Federation of Bosnia and Herzegovina have their weaknesses, reflected in internal incompatibilities, an absence of adequate planning for education and vocational rehabilitation in line with labour market needs, insufficient information on opportunities offered by normative institutional frameworks, general economic conditions, and prejudice

towards and stereotypes of people with disabilities. The situation is further complicated by the low level of education of many individuals with disabilities, their uncompetitiveness in terms of occupation and qualifications on the labour market and uneven development of support services in local communities.

There is also a lack of qualified staff specially trained for work with them. DPOs and individuals with disabilities have started some initiatives to establish their own businesses, but there is a clear gap in terms of support and professional assistance in choosing activities and determining market needs and other relevant information. A new approach is required to the question of labour that promotes service provision, as against the current approach dominated by record keeping and mediation.

Some causes of the low employment rates for persons with disabilities are poor adaptation of working conditions and the work environment to their needs, poor employer motivation, prejudice and distorted attitudes about their employability and performance.

Both entities have been trying to redesign and reform their programs and legislation in the entire field of employment. Policies which refer to the employment of persons with disabilities indicate a commitment to take measures that prioritize and promote it.

One institutional model is represented by recently adopted laws: the RS *Law on the Vocational Rehabilitation, Training and Employment of Disabled Persons*, enacted in 2004, and the FBiH *Law on the Vocational Rehabilitation, Training and Employment of Persons with Disabilities*, enacted in 2010.

The primary purpose of these laws is to provide an institutional framework for the development and implementation of programs for the vocational rehabilitation, training and employment of persons with disabilities on the open market, to be supported, in accordance with special conditions, by the state provision of incentives to stimulate their employment.

Under this model, both entities have established Funds for the Vocational Rehabilitation and Employment of Persons with Disabilities as public institutions to implement their policy.

Vocational rehabilitation processes are conducted within specialized educational institutions and in enterprises established to employ persons with disabilities. Important forms are also carried out in civil society organizations, especially DPOs. Such rehabilitation services within the civil society framework are financed by

projects, hindering standardization, long-term sustainability and inclusion of all who need a given form of support.

RECOMMENDATIONS:

If training is to be provided in using their remaining capacities for successful participation on the labour market, employment, and poverty reduction, the following will be needed:

- Programs that allow persons with disabilities, through better secondary education, advisory services, mediation, job training and lifelong learning, workplace adaptation services and so on, to get and keep well-paid jobs that meet the needs, desires, abilities and capacities of the given individual;
- Public campaigns to inform employers and persons with disabilities about the opportunities and benefits offered by the Law and stimulate employers to employ persons with disabilities;
- Services to support organizations and individuals dealing with the employment of persons with disabilities through projects and allow best practices to be adopted as part of the system;
- Provide the conditions, through habilitation and rehabilitation, that people
 with disabilities need to attain maximum independence, their full physical,
 mental, social and professional capacity and full inclusion and participation in
 all aspects of life;
- Develop professional training and employment programs, including access to lifelong learning programs;
- Review the application of mandatory quotas and other legally-determined incentives for employing of persons with disabilities;
- Support the establishment of specific enterprises to employ people with disabilities, providing financial and professional support, as well as administrative and other incentives to efficient operations;
- Develop services and programs on adapting and equipping workplaces and work environments for persons with disabilities.

1.5. Independent living and supported housing

Under articles 9 and 19 of the *Convention on the Rights of Persons with Disabilities*, signatory states commit to take appropriate measures to provide access to the built environment, transportation, information and communications, including information and communication technologies, and other services and facilities provided to the public, both in urban and rural areas, to persons with disabilities, on an equal basis with others, in order to enable them to live independently and participate fully in all aspects of life.

States are obliged to recognize the equal right of persons with disabilities to live in the community and enjoy the right to choose equally with others and to take effective and appropriate measures to facilitate their full enjoyment of this right, providing for their full inclusion in the community and participation in community life.

The received wisdom in Bosnia and Herzegovina is that people with disabilities, especially women, cannot live independently, have families, take care of themselves or perform everyday activities. There is no systematic support to help them realize an intimate and family life, which would be most clearly reflected in achieving parenthood. Support to most persons with disabilities is provided by parents or other family members. This is particularly true of women with disabilities. There are no programs to support the independent living of intellectually disabled persons. As to rights related to family issues, the law does not deal with benefits for families headed by a person with disability, except in the case of disabled veterans.

Over the past 20 years, people with disabilities have become aware of the possibilities of establishing independent life and a lesser number have achieved a family life.

The declarative commitment to ensure their human rights is not confirmed in practice. No dedicated institutions exist in Bosnia and Herzegovina to develop mechanisms for monitoring the situation in the disability field, even though these issues are the responsibility and duty of the state and its entities.

There have been no programs to build, allocate or adapt social housing units for persons with disabilities, which considerably complicates and limits the inclusion of persons with disabilities, in both private and professional life.

In reviewing the situation regarding accessibility, we conclude that provisions exist at the entity level which determine accessibility standards and the obligations of the relevant institutions for applying them during construction. We believe that that

these accessibility standards are satisfactory, but not applied adequately in practice. Planners, builders and overseers generally do not follow these standards. The result is the following situation: inaccessible buildings, including new build, in an inaccessible environment, with inaccessible public facilities, housing, public transport and information.

Looking at the situation regarding independent living and housing here, we note that while persons with disabilities have traditionally been served in asylum type institutions, the abolition of such traditional institutions is now required by a number of international documents as part of respecting human rights.

Social housing institutions for persons with disabilities in Bosnia and Herzegovina include:

- 1. The Institute for housing children and young people with intellectual disabilities Pazarić
- 2. The Institute for housing persons with intellectual disabilities "Drin"
- 3. The Institute for housing persons with intellectual disabilities Bakovići
- 4. The Duje Centre for the elderly, infirm and homeless "Duje" in Doboj Istok
- 5. The Social and Health care Home for persons with disabilities and others in Sarajevo
- 6. The home for children and young people with developmental difficulties in Prijedor
- 7. The institute for the protection of girls and young people in Višegrad
- 8. The Institute for the treatment, rehabilitation and social protection of chronic mental patients "Jakeš" in Modriča
- 9. The Institute for physical medicine and rehabilitation "Dr Miroslav Zotović"

The traditional segregation model and underdevelopment and poor coordination of existing professional support services hinder the enjoyment of fundamental human rights with an adverse effect on all areas of life for persons with disabilities. This is especially true in the treatment of persons with intellectual disabilities. If they have no family or no one is willing to care for them, they are accommodated in large residential institutions where their fundamental human rights can be subject to violation.

According to a study by Sumero, 1926 persons were accommodated in 5 institutions on social protection in Federation of Bosnia and Herzegovina in 2011: 848 (44.07%) women and 1078 (55.93%) men, of whom 1848 (95.95%) were adults and 78 (4.05%) children.

There are two institutions in the Republika Srpska, in which 361 people were housed: 150 women and 211 men, of whom 311 were adults and 50 minors.

Living conditions, including accommodation, food, clothing, health care, education, leisure activities, sport, cultural and other activities, were at a very low level and are below even minimum standards.

There are too few professionals employed, so that even the most basic conditions for providing the necessary support cannot be met. Currently employed professionals are focused on supporting a large number of people and cannot tailor their support to individual needs and requirements. Many employees at these institutions lack the appropriate expertise for the activities they perform and the quality of the service provided is below standards in this area.

It is important to note that new models of support insist on channelling resources and professional expertise into local communities, with a view to developing supported housing that ensures full respect for the rights of persons with disability. For such support to be effective, a sufficient number of professionals is required, but also the right conditions for providing support. Effective support planning requires good knowledge of the client to provide appropriate support.

The purpose of introducing the community-based service model is to establish a system directed at supporting persons with disabilities in achieving and maintaining an 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 also have equal access to everyday services in the community (regular education, health care, employment and social services).

Together with the cantonal Ministry of Labour and Social Policy and the centres for social work, the Tuzla Canton Association for the Social Inclusion of Persons with Intellectual Disabilities began in 1999 a process to prevent institutionalization, as well as a complementary one of deinstitutionalization of persons with intellectual disabilities. Support has so far been provided to 15 individuals, 8 of whom were not institutionalized as a result, while 7 were deinstitutionalized. As of 2011, Sumero has been working with "OAZA", a Sarajevo Canton association to support persons

with intellectual disabilities, and "Sunce", an association of parents and friends of persons with special needs from Mostar, to facilitate deinstitutionalization and prevent institutionalization, as well as to enable persons with intellectual disabilities to live in the community. The model is currently in a pilot phase and it is expected to receive systematic support from government. The Institute for Social Protection at the Federation of Bosnia and Herzegovina level and "The SUMERO Centre to Support Persons with Disabilities in the Community" received their notification of registration in January 2012.

In 2011, Sumero launched the first supported housing communities for persons with intellectual disabilities, four in Sarajevo, preventing the institutionalization of 10 persons and allowing 2 individuals to deinstitutionalize, and a further one in Mostar, preventing the institutionalization of 3 persons.

Teams in 5 towns in the Federation of Bosnia and Herzegovina (Sarajevo, Mostar, Bihać, Bugojno, Zenica) have now been trained and are ready to offer this form of support.

The personal assistance service is designed to provide support to persons with disabilities fully participating in the social life of their local community, as well as to support them in meeting their basic living requirements. Systemic solutions in Bosnia and Herzegovina still do not, however, anticipate providing personal assistance services and persons with disabilities remain fully dependent on the social welfare system and family support.

Two organizations provide personal assistance services in Bosnia and Herzegovina. In the Federation of Bosnia and Herzegovina, the Sumero Community has been implementing a project for four years of *Support to Persons with Severe Disabilities in Bosnia and Herzegovina*, which includes personal assistance. Fourteen individuals are currently receiving personal assistance services under this project. In the Republika Srpska, while personal assistance services are not legally defined, they have been recognized by the Banja Luka City Assembly and since 2007 included in their extended social protection services, realized together with the humanitarian organization Partner from Banja Luka, which trains and prepares personal assistants for work.

RECOMMENDATIONS:

- To create standards for service quality based on international norms and local practice;
- To provide housing in line with what persons with disabilities want and choose;
- To create programs to transform existing institutions and determine the relevant bodies (entity ministries or agencies) to conduct the process;
- To initiate advocacy processes for building and deployment of social housing;
- To provide support to persons with disabilities in accordance with their needs;
- To ensure assessment services for suitability for independent living;
- To provide training in basic life skills;
- To provide users in existing social protection institutions with adequate conditions for a dignified life;
- To bring workplace organization in the social welfare institutions into line with users' needs.

1.6. Culture and information

Under articles 21 and 30 of the *Convention on the Rights of Persons with Disabilities*, states are obliged to take the appropriate measures to ensure persons with disabilities can exercise freedom of expression and opinion, including the freedom of researching, receiving and expanding information and ideas on an equal basis with others through the usage of all forms of communication, in accordance with their choice.

Bosnia and Herzegovina recognizes the right of all persons with disabilities to participate in cultural life on an equal basis with others and has committed to taking appropriate measures to ensure they develop and use their creative, artistic, and intellectual potential, not only for their own benefit but for the enrichment of society as a whole.

Under the Constitution of Bosnia and Herzegovina, culture and information are in the exclusive jurisdiction of the entities, while in the Federation the jurisdiction is cantonal. This decentralized system barely functions, especially with regard to the rights and needs of persons with disabilities.

Persons with disabilities, especially those with severe disabilities or with sensory and intellectual disabilities, are almost entirely excluded from the mainstream of culture and information. Those with hearing impairments and blind persons have limited access to information in some forms of communication. Government departments have no sign language interpreters, while persons with impaired vision may have difficulties obtaining information in written form, as Braille printers are nowhere used. The media in Bosnia and Herzegovina present disability issues in an unacceptable manner, often as tragedy or sensationally, maintaining stereotypes.

Accessibility of the physical environment and of services and information is a precondition for making social contacts, independence and inclusion in everyday life.

There are no specialized programs in culture and art for persons with disabilities, while regular programs do not provide adequate accessibility to facilities and information. Persons with impaired vision lack access to culture and art because of failure to use either Braille or provide information in audio or large print format. DPOs' activities have included local levelinitiatives on the issue of their cultural life, but they have been insignificant in scale and unsustainable over the long-term, due to funding instability. The current situation fully excludes persons with disabilities from participating in cultural and artistic life.

Both entities have public libraries for the blind, but their status, especially that of the one in the Federation, is inadequately defined and they are inadequately financed. The number of books published in Braille or in audio and large print formats is insufficient for the needs of blind persons, whose organizations have no influence on the management of the institutions or on selecting the books for publication.

The problem of access to information is particularly obvious for people who are blind or visually impaired or have hearing impairments or intellectual disabilities. Neither public nor private broadcasting services provide sign language interpretation or adapt their programs to be more accessible to blind persons or to enable those with hearing or vision impairments to attend to more varied program content. Only one magazine is published in Braille in Bosnia and Herzegovina. It is quarterly and is financed by the Republika Srpska Society of Blind Persons from its own resources. As to magazines in audio format, 5 are published, 4 by organizations of blind persons: The RS Society of Blind Persons, the Sarajevo Canton Association

of Blind Persons, the Tuzla Canton Association of Blind Persons and the Herzegovina-Neretva Canton Association, while just one magazine is published by the Library for Blind Persons in Bosnia and Herzegovina.

RECOMMENDATIONS:

To ensure people with disabilities can exercise their rights in the fields of culture and information, the following are necessary:

- A legal framework for providing access to information in accessible formats, as well as to cultural institutions and programs;
- Support services that facilitate access to cultural institutions and their programs, historical monuments and natural resources;
- Sign language interpretation services to ensure access to information in public institutions and the media;
- Services for publishing magazines and other literature in Braille and audio and large print formats and in simplified format for persons with intellectual disabilities;
- Services for preparing and publishing information in simplified format for persons with intellectual disabilities;
- Programs, including financial support, aimed at encouraging DPOs to include as many of their members as possible in cultural activities.

2. Recommendations for introducing support services for persons with disabilities

As the community's relationship with persons with disabilities undergoes transition in Bosnia and Herzegovina, change will be required in the approach to various forms of support to be provided by the community to the various categories of persons with disabilities, as well as how to implement them.

Analysis of previous ways of delivering support for persons with disabilities suggests that local communities have not been providing even minimum levels of support, even in those cases where the obligation is already set out in law. Redefinition of the legal framework and standards is required to facilitate mandating of appropriate community-based support mechanisms on the basis of clear procedures.

A significant number of studies, supported by commitments expressed in key strategic documents and reform 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 Bosnia and Herzegovina will be one based on a mixed model, including a range of local services and financial forms of support. This approach also makes it possible to provide different forms of support and services that take into account the specificities of different categories of persons with disabilities.

Certain key aspects of organizing services for persons with disabilities need to be taken into account if they are to be organized in accordance with the needs of their prospective users, as well as meeting the other criteria of service delivery.

We set out here our main recommendations for ensuring that that different actors interested in introducing a system of services for persons with disabilities and potential users recognize and accept the benefits, as well as the social and economic justification of introducing new forms of support for persons with disabilities.

2.1. Before establishing the new support system

The various parties interested in improving society's approach to persons with disabilities have to accept the need for developing a new model of support.

A new model should provide different forms of support based on a range of services, provided by the state, but developed at the local level and based on the needs of people with disabilities, allowing for their optimal inclusion and integration into the community in all areas of life.

In line with the international documents it has signed and ratified (the *Standard Rules*, the *Convention on the Rights of Persons with Disabilities*, etc.) and international standards, the state should meet certain conditions (adoption and consistent implementation of legislation in the field of disability) for eliminating obstacles to the social inclusion of persons with disabilities.

The state should develop, promote and implement policies aimed at transition from previous forms of support to a system of providing services for persons with disabilities in the community. This must be in line with the entities' disability policy and strategies.

2.2. A possible legal basis

Insofar as new approaches to disability are based on inclusion and the legal regulation of disability issues under the jurisdiction of particular ministries, the system of support services for persons with disabilities can be dealt with under a number of different laws regulating the various areas. This would ensure appropriate services for persons with disabilities were defined as integral to the laws governing relations in each area. The advantage is that the institutions responsible for ensuring implementation of the law regulating a given area would also be responsible for providing services to persons with disabilities. Awareness of the need to introduce new services and equalize opportunities for persons with disabilities with those of other citizens would thus be raised within the relevant institutions. Such a model would entail regulating social protection services under the laws governing each particular area, while health care services would be determined under the laws on health care and health insurance and education services by the laws on preschool, primary, secondary and higher education.

Given the reform processes currently underway in various areas, one way of legally positioning the system of services for persons with disabilities would be through

advocacy to have them defined by amendments in the relevant areas, before the introduction of the support services for persons with disabilities.

The disadvantages of such an approach relate to how relevant the various levels of governance are in different areas, as the same services may be differently regulated in different parts of the country.

Another solution is special entity-level laws dealing comprehensively with all aspects of support for persons with disabilities and the development of various support services in the local communities. In drafting such laws, one could draw on the experience of states that have already followed this path to providing support for persons with disabilities.

Regardless of which option is taken, it is crucial that drafting of a state-level document be advocated to serve as a framework for regulating the basic principles of introducing a community-based system of support for persons with disabilities.

2.3. Ways to determine the need to introduce particular services

The key issue for those hoping to organize community-based services for persons with disabilities is how to define their type and scope for particular groups at given times and places.

One way is to examine the need for the various types of service in a particular area. This could be done in such way that the relevant institutions periodically initiate meetings of all those potentially interested in the services so as to discuss service types and implementation.

One way of determining needs for support services would be to use the International Classification on Functioning, Disability and Health. Its comprehensiveness gives this model great potential for disability assessment, as well as for defining the needs and priorities of the expected users of a community-based service.

Given the different distribution of responsibilities, including the obligation to provide these services, over different levels of government in different parts of the country, the most appropriate way of determining their type and scope could be through periodical surveys of people with disabilities and others potentially involved in organizing and delivering services.

Such research should be commissioned by the government institutions responsible for the specific areas and conducted by universities, professional associations, agencies, or DPOs.

2.4. Which services to provide

In selecting services for development, the results of prior studies should be considered, along with the social and financial impact of introducing particular services and well as their impact on the quality of life of people with disabilities.

Areas that might be developed and could improve the social inclusion of service users are:

- Support for independent living (both preventing the placement of persons with disabilities in institutions and promoting deinstitutionalization);
- Personal assistance;
- Person-centred planning;
- Day centres for children and others with disabilities (occupational therapy, acquisition of basic life skills, self-advocacy, self-determination);
- Counselling, accessible information;
- Inclusive education;
- New skill development;
- Support to employment;
- Social or supported housing;
- Rehabilitation services.

Support services should provide for the direct meeting of previously defined individual needs through organized community-based services, with all stakeholders participating, based on pre-met criteria with guaranteed quality and access for all who need them.

2.5. Availability

For services to be available to all persons with disabilities who need them, given that previous support methods were based solely on cash benefits, the following are necessary:

- Information campaigns regarding the benefits of support services for persons with disabilities and the advantages they offer over previous methods;
- Information on available services and how to access each of them;
- Physical accessibility and accessibility of information on services provided;
- Equal availability of services for everyone with disabilities in both urban and rural areas, including of services for both men and women with disabilities, given the need for some services to be gender appropriate;
- Availability to all age groups, taking into account each group's specificities and adapting service delivery accordingly.

Campaigns for introducing support services for persons with disabilities should be conducted by the relevant state institutions, with the support of DPOs and the media.

2.6. Assuring standards

The legal framework for the establishment and operation of community-based services for persons with disabilities should make clear the importance of standardization the services in question.

The regulations for standardizing each service should take into account valid international standards for providing social services to persons with disabilities as well as local provisions in the field.

The standards for establishing particular services should precisely define:

- The location requirements for organizing and delivering the services in question;
- The necessary equipment;
- The personnel structure and qualifications;
- Safety and security procedures and standards;

- Procedures for accessing each service, record keeping and monitoring delivery;
- Procedures to protect users' privacy and ensure a possibility of appeal;
- Procedures for supervision, monitoring and evaluating the quality of services delivered;
- Procedures for user participation in designing service delivery modalities, as well as in the decision-making process concerning services;
- Additional standards will need to be developed further, taking into account the specifics of the services being delivered and of the groups using them.

2.7. Possible certification methods

Ensuring that organizations and other institutions have adequate confirmation of having met the conditions for organizing a particular service for persons with disabilities will require methods and conditions for certifying them.

We recommend two commonly used methods of certifying:

- 1. Certification can be obtained from a relevant institution, regardless of when the service-delivering institution or organization considers it actually met the standards:
- 2. A certifying institution may periodically announce a call for certification and all organizations or institutions which meet the standards set can apply for certification of the service they offer.

The practice is for certification to be kept separate from the call for applications for co-financing or funding of service by government institutions.

The certification process should involve:

- Submission of the necessary documents and evidence of meeting the standards for organizing and delivering a particular service;
- Checking the documentation and inspection of the space and equipment required to provide the service;
- Review and evaluation of required procedures.

The provisions regulating certification should also provide for some form of periodical certificate renewal, as well as revocation, should the organization or institution fail to meet the standards for conducting the service.

2.8. Possible supervision models

Supervision of support service provision to persons with disabilities and of their quality should also be legally regulated and should involve:

- The relevant state institutions:
- Internal monitoring;
- Supervision by users, performed by specialized bodies established by service users.

2.9. Possible models for service funding

Funding modalities for services for persons with disabilities differ, depending on the structure of governance and the model of support developed in a given country.

Given Bosnia and Herzegovina's structure of governance and the distribution of responsibilities in various fields between the entities and lower levels of government, we believe the most appropriate model of funding to be a mixed one, which could involve covering service costs from multiple sources, including the municipality, canton and entity, and even the possibility of funds being provided from foundations or international donors.

To ensure that particular services are available to persons with disabilities throughout Bosnia and Herzegovina, entity regulations should deal with covering the costs of the basic service package, leaving lower levels (cantons and municipalities) to ensure the additional funds needed for full financing.

Individuals with disabilities should perhaps also contribute to covering the costs of services they are using, if the service provided is wider in scope that the professional team deems strictly necessary. These funds could be kept separate from the funds earmarked for payments or fees for assistance and care or other income intended as support to equalization of opportunities.

Government institutions should cover fully the organizational costs of all services providing persons with disabilities support in the exercise of their human rights and equalization of opportunities, without limiting usage, regardless of the material status of the individuals with disabilities wishing to avail of those services.





MyRight (SHIA)* is an umbrella organisation within the disability movement which works at the request of 30 member organisations.

The disability movement has a long tradition of work based on respect for human rights.

The goal of our joint work is to strengthen local partner organisations' capacity for effective advocacy of their members' rights. MyRight's role is to provide administrative support for member organisations. We also provide quality assurance of their projects. Our vision is of a society where everyone's equality and rights are respected. This is why we provide support for bringing people together into strong organisations that can advocate for respect for the human rights of persons with disabilities.

Programme for 2011-2013 in Bosnia and Herzegovina

The main goal of the SHIA (MyRight) programme in Bosnia-Herzegovina is to increase local disabled persons' organisations' capacity with regard to their knowledge and mechanisms for advocating for their members' rights under the UN Convention on the Rights of Persons with Disabilities.

* In 2012 SHIA was renamed MyRight - empowers people with disability





