



BEYOND DE-INSTITUTIONALISATION:

The Unsteady Transition towards an
Enabling System
in South East Europe

2004

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THE DISABILITY MONITOR INITIATIVE

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Christophe Smets - Demonstration on Accessibility in Tirana, Albania



FOREWORD

THE DISABILITY MONITOR INITIATIVE FOR SOUTH EAST EUROPE

For decades the disability movement, despite its diversity, has been unifying its voice to promote a global shift of paradigm: moving from a charity and medical approach to consider disability as a human rights issue. Acknowledging this change, for the past three years, the UN has been defining a convention that aims to ensure that people with disabilities fully enjoy their rights as anyone else in society. People with disabilities from around the world are present in this process represented by their organisations and their personal testimonies which universally conclude that discrimination, poverty, exclusion are still the main characteristics for the 500 million people with disabilities living around the globe.

In the frame of this global movement some initiatives are emerging at national and international levels to monitor the situation of people with disabilities. Most recently, the International Disability Rights Monitor launched a regional report on the Americas in 2004¹.

In South East Europe, the legacy of an overprotective medical approach to disability in addition to the difficult transition to a market economy including the collapse of the social welfare system and 15 years of civil conflict, have contributed to the exclusion and marginalisation of people with disabilities such that they are over represented amongst the most vulnerable populations in the region.

All the countries in the region face similar challenges regarding transition and disability issues. They also share a common perspective in terms of the European Union accession process. As a result, there is a strong political momentum for reforms in all sectors.

With the new disability paradigm arising, there are new roles and responsibilities for stakeholders from the public, private and non-profit sector. The new political, economical and social context beginning to take shape in the region gives people with disabilities and their allies the unique opportunity to participate in building an enabling society rather than a disabling one.

The Disability Monitor Initiative for South East Europe aims at supporting local stakeholders to face these new challenges. Its objective is to monitor how local organisations, authorities, governments, and international agencies develop and support social innovation and policy reforms that promote and enable the full participation of people with disabilities.

This first report addresses the unsteady transition towards an enabling system aimed at facilitating the full participation of people with disabilities. During the past decade, many initiatives have taken place in the region to develop community-based services and, for instance, an inclusive approach to education.

However, there are rarely comprehensive strategies and policies put in place that go beyond a humanitarian approach to de-institutionalisation to the building of a rights-based enabling system. Local stakeholders who are initiating this change are struggling to make community-based services sustainable while current social service institutions are still very far from fulfilling their mission towards people with disabilities.

Because each local initiative and reform effort uses many of resources, and because these resources are difficult to find within the transitional context of South East Europe, stakeholders have an obligation to share experiences and learn from one another. With the Disability Monitor Initiative, Handicap International proposes a tool in which field professionals and activists talk to decision and policy makers thus facilitating the sharing of knowledge and best practices. The Disability Monitor Initiative would like to serve as a vector for building networks and influencing the change process as well.

This first report is a base for further research and the Handicap International South East Europe team is aware that some very interesting initiatives or relevant sectors might not be covered. Any comments, additions, or propositions are most welcome and can be sent to disabilitymonitor@hi-see.org.

Finally Handicap International would like to thank the whole team for its work as well as all the local organisations, institutions, and individuals that contributed with their meaningful experiences and knowledge. We would also like to thank the U.S. State Department via the International Trust Fund as well as the UK Department for International Development for their financial support.

The time for change has come and we hope that this initiative will help to support all stakeholders in their efforts to achieve a sustainable move towards a society for all.

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¹ This report is produced by the Center for International Rehabilitation, Chicago. www.disability.ws

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ACRONYMS AND ABBREVIATIONS

- ADA - Americans with Disabilities Act
- ADS - Association of Disabled Students
- API - Association for Promoting Inclusion
- ASCHF-R - Support Association for the Physically Disabled Children from Romania
- BiH - Country of Bosnia and Herzegovina
- CBR - Community-Based Rehabilitation
- CBS - Community-Based Services
- CIL - Centre for Independent Living
- CIR - Centre for International Rehabilitation
- CoE R (92) 6 - Council of Europe Recommendation No. (92) 6 on a coherent policy for people with disabilities
- CSW - Centre for Social Work
- DCP - Disability Creation Process model
- DFID - Department for International Development
- DPI - Disabled People International
- DPO - Disabled People Organisation
- EDF - European Disability Forum
- EU - European Union
- FYROM - Country of the Former Yugoslav Republic Of Macedonia
- ICF - International Classification of Functioning, Disability and Health (ICF) (published by the World Health Organisation)
- ICIDH - International Classification of Impairments, Disabilities, and Handicaps (the former World Health Organisation classification model)
- IC Lotos - Information Centre Lotos
- ICACBR - International Centre for the Advancement of Community-Based Rehabilitation
- ILO - International Labour Organisation
- INGO - International Non-Governmental Organisation
- IPPLG - Inter-Party Parliamentary Lobby Group
- ISO - International Organisational Standards
- ISPO - International Society of Prosthetics and Orthotics
- MQE - Measurement of the Quality of Environment
- NGO - Non-Governmental Organisation
- OSCE - Organisation for Security and Cooperation in Europe
- PHC - Primary Health Care
- PMR - Physical Medicine and Rehabilitation
- PORAKA - Republic Centre for Supporting People with Intellectual Disabilities
- PRSP - Poverty Reduction Strategy Paper

SEE - South East Europe (NOTE: In this report, the region of South East Europe consists of the following countries: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Macedonia, Romania, Serbia and Montenegro and the UN administered province of Kosovo)

SAA - Stabilisation and Association Agreement with the European Union

SAP - Stabilisation and Association Process with the European Union

SCF - Save the Children Fund

Share-SEE - Self Help and Advocacy for Rights and Equal opportunities in South East Europe, a project that enhances the disability movement in South East Europe

SIF - Social Innovation Fund

SITAP - Social Insurance Technical Assistance Project

SFRY - Socialist Federal Republic of Yugoslavia

SLSP - Survey on the Living Standard of the Population

UN - United Nations

UNDP - United Nations Development Programme

UNICEF - United Nations Children's Fund

WHO - World Health Organisation



INTRODUCTION AND OVERVIEW



INTRODUCTION AND OVERVIEW

THE PARADOXICAL SITUATION OF PEOPLE WITH DISABILITIES IN SOUTH EAST EUROPE

People with disabilities in South East Europe are living a paradoxical situation. The legacy of an over protective care system and a disabling society together with the effects of conflicts, the collapse of the economy and state resources, have combined to create living conditions which have never been worse for people with disabilities. At the same time, the various reconstruction and reform processes linked to the transition have created real opportunities for people with disabilities to influence and promote the development of enabling systems and inclusive societies.

THE QUESTIONABLE RESULTS OF HUMANITARIAN AID ON DE-INSTITUTIONALISATION

During the "Balkan" crisis, disability has been seen mainly through a humanitarian perspective. The discovery of terrible violations of basic human rights in residential institutions, and the isolation of people with disabilities have led to massive injections of emergency aid in order to temporarily improve the situation. As a consequence, this aid has partially contributed to maintaining many people in residential institutions. A strong focus has been placed on a necessary de-institutionalisation process and many initiatives have supported this process. Rarely, though, have these initiatives been incorporated into a long term strategy with a clear understanding of the goal that is the inclusion and full participation of people with disabilities in society. This lack of perspective has led to "dramatic confusion" between the transformation of residential institutions and the development of an enabling care system. For example, the director of a residential institution in Serbia spoke to Handicap International about how proud he was to have implemented de-institutionalisation because he succeeded in building a group home within the confines of the existing institution, which is far from any urban centre. Stakeholders should never forget that de-institutionalisation is a complex process and that it is only one step towards the creation of an inclusive society.

THE DISABILITY MONITOR INITIATIVE: EQUAL OPPORTUNITIES AND FULL PARTICIPATION AS A GOAL

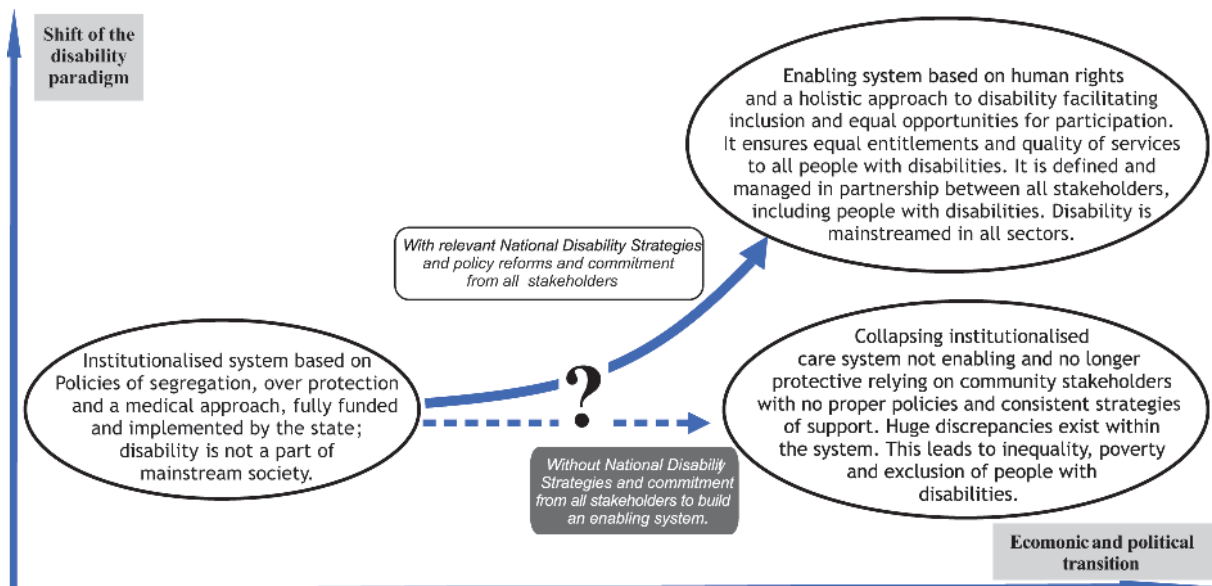
The Disability Monitor Initiative for South East Europe and the report "Beyond De-institutionalisation, the Unsteady Transition towards an Enabling System for People with Disabilities in South East Europe", aim to contribute to support stakeholders involved in long-term processes that have equal opportunities and full participation as a goal. There is a risk that the ongoing efforts will stop when so called "basic human rights" are no longer violated. In recent decades another understanding of what the enjoyment of human rights of people with disabilities should be has arisen: no more and no less than those of any other citizen. While the United Nations is working to define a convention aimed at ensuring the full enjoyment of all civil, political, social, economic and cultural rights by people with disabilities, stakeholders in South East Europe have to go beyond seeing disability as a humanitarian, health or social protection issue. Instead, they should see it as a human right and global policy issue and therefore place it into the overall reform agenda rather than placing it into disability-specific initiatives.

THE CHALLENGES OF A TWO FOLD TRANSITION

All stakeholders, civil society (including representatives of people with disabilities), public authorities at local, national and international level are facing the challenges of a double transition: the shift of the disability paradigm from a medical to a holistic one based on human rights, as well as the transition from a command to a market economy. One of the concerns of the disability movement is that the reform of the care system affords people with disabilities less "protection" than previously without building an enabling system giving them equal opportunities to participate in society.

The report advocates for this double transition. Stakeholders must redefine their role with greater involvement of civil society in policy-making and service

Scheme 1. The challenges of a two fold transition



provision, states need to support the development of community-based services and ensure equality of rights and treatment for all their citizens. Most importantly, all stakeholders should share a common goal: reforming the system to build an inclusive society, a society for all (Scheme 1).

A REPORT FOR STAKEHOLDERS INVOLVED IN THE CHANGE PROCESS

Although South East Europe in its entirety is considered, the report focuses on countries of the western Balkans, including: **Serbia and Montenegro, the UN administered province of Kosovo, Albania, Macedonia, and Bosnia and Herzegovina.** Where relevant, highlights from neighbouring countries more advanced in the EU accession process such as Croatia, Bulgaria and Romania are presented.

The information presented is based mainly on the use of primary sources. It is not intended to be exhaustive but informative. The data about the existing care system for people with disabilities and the initiatives for change was gathered largely through field interviews with key stakeholders in the reform process, such as government authorities, local

NGOs and DPOs, Handicap International field staff, international agencies and expert consultants. In addition, data was collected from existing reports and documents produced by various stakeholders over the past decade. As disability statistics are rarely available in the region, there is little formal documentation on the actual situation of persons with disabilities. The report therefore combines qualitative findings with analytical assessments, useful in identifying priorities for effecting the change to an enabling system.

Using the description of **good practices** in various service fields, the report aims at propagating the lessons learned from those experiences, analysing the conditions necessary to sustain and replicate these types of services. At the end of each main chapter, a **spotlight** provides the reader with an in-depth description of a given successful experience in one country and of the organisation originally responsible for the development of this service. Throughout the paper, selected **interviews of persons with disabilities** illustrate a range of experiences within an institutionalised care system, or how a person can achieve social participation. Often, the same person can experience the two aspects of the system, which is characteristic of the region's transitional systems.

I. SHIFTING THE DISABILITY PARADIGM TOWARDS FULL PARTICIPATION

Understanding disability: the change from a medical to a social and human rights issue

The first part of the report describes how the dominant portrayals of disability within a society determine the way in which people with disabilities are cared for and their place in society. Equal opportunities and full participation for people with disabilities can therefore only be achieved through bringing about an in-depth change in this disability paradigm.

Over the course of the late XXth century the so-called "**social model**" (which views disability as the result of social barriers that prevent people with disabilities from participating into the society) arose. This model opposed the previously dominant "**medical model**" (in which disability is considered as an individual pathology) that had until then underpinned much of service provision for people with disabilities all around the world. Within this social stream, the **Independent Living philosophy** was developed by organisations of people with disabilities, placing the emphasis on the concepts of personal control, rights and responsibilities.

Latterly the development of **holistic models** brought about a global understanding of disability, taking into consideration all dimensions. Such a holistic approach recognises the inputs from various fields (biomedical, (re)habilitation, social, human rights). This holistic approach is fundamental for the development of comprehensive and inclusive disability policies and for planning and implementing interdisciplinary and individualised services. The **Disability Creation Process** model employs such a holistic approach: it defines Disability as a disturbance in a person's life habits as the result of a dynamic interaction between personal factors (impairment or disability) and environmental factors (obstacles).

The development of international legislation on the rights of people with disabilities during the 1970s also accounts for this shift in paradigm from the medical to the social model of disability. Among those, the adoption by the *UN General Assembly of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities*² in 1993, presented disability rights as an equal opportunity issue rather than a special needs issue. For South East European countries at various stages of an EU association or accession process, a key legal instrument is the *Council of Europe Recommendation No. R (92) 6 of the Committee of Ministers to Member States on a Coherent Policy for People with Disabilities*³.

Institutionalised care systems leading to dependency and social exclusion

The legacy of an institutionalised care system in South East European countries still largely determines the service delivery for people with disabilities. An "**institutionalised care system**" is a system of medical, social, educational, employment and other support services that is designed with the aim of protecting people with disabilities, in which the control of the services and thus of the lifestyle is ensured mostly by the professional experts in specialised institutions. Such a system results in **people with disabilities losing control over their own lives**, and leads to **social exclusion**. The absence of alternative support services and the low level of information available on rights, services and diagnosis often place people with severe disabilities - or their parents - only having the choice of either being housebound or placed in a residential institution. It has a "**disabling effect**", as it prevents people with disabilities from reaching their full potential in terms of independence and social participation.

Beyond de-institutionalisation, the crucial development of an enabling system

De-institutionalisation of disability, in terms of services such as social welfare services, education, employment and medical health care, has been the major trend in Western Europe and North America since early 1970's. Experience has shown that in order to ensure equal participation of people with disability in society, de-institutionalisation should be considered in a much more comprehensive manner than a simple movement of individuals out of institutions and into the community. **De-institutionalisation** is actually "**the process by which a care system, originally aiming to protect people with disabilities by excluding them from society, transforms into a care system that aims to facilitate social participation by offering a wide range of services provided at community level, and respects the principle of choice and decision**".

The ultimate goal is the establishment of an **enabling system**, oriented towards supporting people with disabilities reaching and maintaining their optimal level of independence and social participation, taking into account their personal factors, their environment and their expectations. In such an enabling system, the person has access to a variety of services that give him/her **the opportunities and the choice to decide** about his/her life-style. **Equal access to mainstream services** existing at the **community level** (ordinary education, health, employment and social services) is ensured, with **individualised support services**, and referral to specialised services when needed. Access to individualised and comprehensive **assessment, information and counselling** is also needed, in order to allow a real choice. In an enabling system, people

² UN General Assembly resolution 48/96 of 20 December 1993.

³ Adopted by the Committee of Ministers on 9 April 1992 at the 474th meeting of the Ministers' Deputies

with disabilities and their representatives participate in the planning, implementation and evaluation of measures that concern them. To achieve this goal, the de-institutionalisation requires a radical shift in the disability paradigm; from the medical paradigm underlying the institutionalised care system, towards a holistic paradigm based on the principles of rights and full participation.

II. THE UNSTEADY DEVELOPMENT OF COMMUNITY-BASED SERVICES IN SOUTH EAST EUROPE

The legacy of overprotective care systems for people with disabilities

The institutionalised care systems for people with disabilities in South East Europe were part of the socialist framework of the universal social welfare system, which provided for families in terms of guaranteed jobs and pensions, child allowance and in-kind benefits such as education, housing and health care. People with severe or combined disabilities, as well as other categories of persons whose needs for individual support were not covered by this 'universal protection', were often directed towards institutional care where available. The planning of institutional care facilities was done at the central level, often using the logic of providing specialised institutions by type of disability. These institutions were often located in remote areas in the countryside, and their size varied but could accommodate up to 1,000 beneficiaries.

Despite these common principles, significant differences existed between the various South East European countries. The organisation of the social protection system in former Yugoslavia reflected the specificity of its self-management system, with decentralised structure and financing mechanisms. On the other hand, the systems in Albania, Bulgaria or Romania were highly centralised. Whilst Bulgaria and Romania had a common tendency to encourage the separation of children from their parents, former Yugoslavia tended to promote the protection of the family as a social unit. In former Yugoslavia, the social protection system was relatively comprehensive and well developed. Assistance to persons with disabilities in this country was partly influenced by modern concepts and international resolutions, which Yugoslavia supported. However there were discrepancies between regulations and practice, which became more and more evident with the worsening of the economy and the political crises.

People with disabilities among the groups most affected by wars and socio-economic transition

In each country of the region, the post-communist era saw the **collapse of the social protection system**. During the 1990s, within the context of economic crisis, decreasing public financial resources quickly became insufficient to guarantee the social and health care benefits as set by law, especially for the growing part of the population falling into poverty. Armed

conflicts following the breakdown of former Yugoslavia brought about additional destruction, displacement of populations and collapse of pre-existing social, education and health care systems. People with disabilities were among those most affected by those changes. Worrying inequities in access to rehabilitation and health services appeared. In an environment of high unemployment, people with disabilities are usually excluded from the labour market, and more prone to the risk of falling into poverty.

Nevertheless, in each country today, the evolution of the care system for people with disabilities varies according to the organisation of its social protection and medical care systems, and according to the reform trends opted for in each domain. In Bosnia and Herzegovina for instance, the complex organisation of political institutions resulting from the Dayton peace agreement gave birth to fragmented social protection and health care systems, with significant discrepancies between types of social benefits and rehabilitation services people with disabilities may get from one canton or one entity to another. In contrast, Serbia and Montenegro saw a strong recentralisation of those services during the 1990s. Albania still suffers from the legacy of its huge backwardness in terms of support services for persons with disabilities. In the UN administered province of Kosovo the standards of medical and social care remain dramatically low and the absence of a social security system is affecting people with disabilities even more than the rest of the population.

The emergence of inclusive and community-based services

Despite the worsening of living conditions for many people with disabilities due to these adverse socio-economic factors, the careful analysis of the systems of services available for them in the region also reveals the **development of an increasing number of inclusive and holistic community-based services**. Each of those initiatives contributes to a process of de-institutionalisation, which is slowly being implemented in the region. Indeed, if one puts together all the good practices that exist in the various fields of services (social services, education, health care, labour...etc) at a small scale in the region, the picture of an enabling care system appears, consistent with international standards and a model of society where people with disabilities would tend to be included in the community as are all other citizens, with equal rights and opportunities.

However, none of the countries considered in this report have developed a comprehensive strategy tackling all the aspects of this multifaceted de-institutionalisation process. Analysing each field of services, identifying the main obstacles inherited from the former institutionalised care systems, and highlighting the lessons learned from existing community based or inclusive initiatives, the report sets out priority issues to be addressed in order to build an enabling system.

Medical care: the need to ensure an equal access to Primary Health Care (PHC)

People with disabilities remain too often excluded from the mainstream health care services, and are systematically oriented towards specialised medical institutions. Nevertheless, in some places (like the developmental counselling centres existing in Macedonia or in Serbia, or in the 60 community based centres recently established within the public primary health care in Bosnia and Herzegovina) they can receive comprehensive medical services and (re)habilitation care within the public PHC level. Radical improvements in health care systems are needed to achieve this on a larger scale:

- Efforts should be made to mainstream disability in PHC, which implies a sensitisation of all health professionals such as physicians and nurses during their studies,
- There is an urgent need to develop (re)habilitation services within PHC, in order to improve access to (re)habilitation services, and to achieve an efficient continuum medical care - (re)habilitation.

(Re)habilitation: from specialised hospital care to comprehensive community-based services

Too often in the region, (re)habilitation remains narrowed down to medical treatment by specialists such as defectologists and physiatrists. Except for persons with mild disabilities, this treatment is mainly provided within specialised rehabilitation institutions. The organisation of (re)habilitation care remains very hierarchical, overspecialised and fragmented, resulting in stereotyped treatments, which usually do not take into account environmental factors and individual expectations. There is a lack of (re)habilitation services at the community level. The quality of care within existing medical (re)habilitation structures is very unequal, due to the absence of quality standards and the lack of high-level professionals and management capacities.

There are however many examples of recently established community-based services such as Day Care centres which have proved to provide quality services, based on holistic approach to disability and a more active role of users in defining the (re)habilitation plan. The example of the Karin Dom Foundation in Varna (Bulgaria) shows how such a structure can become a resource and training centre that contributes to the dissemination of holistic and interdisciplinary rehabilitation approaches to professionals.

To improve the access and quality of services for people with disabilities, the following priorities need to be dealt with:

- Develop (re)habilitation services at community level,
- Establish professional standards and quality standards for (re)habilitation professionals,
- Develop the profession of occupational therapist as a key element to improve the level of independence of people with disabilities by working on the interaction with the environment,

- Develop coordination, interdisciplinary approach and networking,
- Improve the involvement of users and their representatives in the development and evaluation of community-based (re)habilitation services.

Support services: towards greater accessibility to increase the level of independence of people with disabilities

Shifting from an excluding approach to provision of services to one that gives opportunity for the person with disability to choose is possible. Assistive technology, devices and services such as orthopaedic aids, sign language interpreters and personal assistance services among others, are key preconditions for the participation of people with disabilities. These services exist in the region but access is very limited due to the lack of resources allocated to their development. For instance, the personal assistance services, which is a key element of an enabling care system, exists mainly in Serbia and its implementation by the **Centre for Independent Living** is project based. In order to promote these support services, at community level, the following are recommended:

- Organisations of people with disabilities should play an important role in the planning of support services, and in the training and sensitisation of various professionals on accessibility and other disability issues,
- Equal financial accessibility to assistive devices for persons who need them should be ensured, notably through the establishment of equitable and realistic cost-recovery systems. This issue must be tackled within a broader frame of defining realistic basic health care packages, transparently and with participation of organisations of persons with disabilities,
- Regional and international cooperation is needed to develop formal professional education in the fields of ortho-prosthetics in order to improve the quality of services,
- There is a need of redirecting resources from institutional care towards the development of these support services.

Education: from segregation to inclusion

The inherited segregating special education system still represents the main educational opportunities for most children and youth with disabilities. However, in all countries certain initiatives for improving access to education for children with disabilities, both at the legislative level (often with limited impact due to the absence of enforcement mechanisms) and through pilot projects have been implemented. The main obstacles to inclusion and integration have been shown to be prejudice and lack of knowledge about disability by teachers and children without disabilities and their families, and resistance by professionals in the special education system. However some initiatives, such as the project of inclusive education conducted by **DUGA** - a local NGO - in Bosnia and Herzegovina in collaboration with Ministries of Education show that those obstacles are not insurmountable.

As stated in the Salamanca Declaration⁴, "*regular schools with an inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all...and ultimately the cost-effectiveness of the entire education system*". With that objective in mind, the following priorities have been identified:

- To prepare children for entering into mainstream education, children with disabilities should have prior access to preparatory and additional support. In a transition process this could be provided within community-based programs, such as Day Care centres, while working on mainstreaming regular educational systems,
- Disability must be mainstreamed within education of teachers,
- Defectologists and special educators should develop a greater support and reference role.

Vocational guidance and employment: from sheltered workshops to mainstream employment

Adding to the legacy of a system of vocational training and guidance based on an outdated approach of sheltered employment, and on vocational training based on medical diagnosis rather than choice and abilities, the rapid increase in unemployment in all countries in the region has reinforced the exclusion of people with disabilities from employment. Despite this context, various experiences show that it is possible to have a positive impact on access to employment without major investment and resources, as is the case with the **Association for Promoting Inclusion (API)** programme of supported employment in Zagreb.

The main priorities in the field of access to employment should be:

- Vocational guidance should be part of the regular employment bureaus where staff should be sensitised on disability issues,
- Vocational training facilities for people with disabilities should provide competitive training and thus give opportunities for real employment afterwards,
- Incentives should be provided to employers to hire people with disabilities,
- Awareness raising campaigns to overcome prejudice regarding workers with disability,
- Increased collaboration between DPOs and Unions of Workers' organisations in order to mainstream disability in these organisations,
- A system of sheltered workshops may still be needed during a transition period, as well as for some

persons with disabilities whose needs cannot be met within the regular labour market,

- Supported employment should be developed and some resources should be reoriented to facilitate that development.

Moving away from residential institutions: development of alternative housing and community-based residential living

Whilst the number of persons hosted in residential institutions tends to rise in most of the countries due to the context of growing poverty⁵, the living conditions dramatically worsened in many of those institutions⁶. This occurs despite of the development of alternatives to residential care, such as Independent Living homes of **Association for Promoting Inclusion** in Croatia, or the Family Group Homes Programme of **Motivation** in Romania. To radically transform this system of residential institutionalised care, the main priorities are:

- To continue to develop supportive services at community level, in order to ensure a chain of needed services,
- To the widest extent, mainstream disability within ordinary services, but also provide specialised services for supported living and personal assistance,
- To connect these types of services with inclusive education and mainstreaming of employment in order to ensure that services developed do not end up to be another form of exclusive specialised services for persons with disabilities,
- To progressively close most of these institutions and transform some of them into resource centres or respite care facilities.

The need to define coherent strategies for the development of an enabling system, building on existing alternatives

The analysis of the systems of services for people with disabilities in South East European countries shows the picture of a system in transition, where the legacy of the old system still causes resistance to the emergence of a community-based and inclusive system of services. Many services being developed are still exclusively for people with disabilities and developed by professionals without involvement of users or their representatives (DPOs). Even though a process of change towards a more enabling system has been initiated, this de-institutionalisation process remains unsteady and uneven, being rather the sum of isolated initiatives than the coordinated implementation of a comprehensive and coherent strategy. Many of those initiatives are facing difficulties reaching sustainability.

⁴ Salamanca Statement on Principles, Policy and Practice in Special Needs Education (June 1994)

⁵ David Tobis estimated that at least 4% of people with disabilities in the countries from the former Soviet Union and Central and Eastern Europe still lived in residential institutions in 1995. "Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Soviet Union", (2000):22.

⁶ Alexandre Zouev, "Generation in Jeopardy: Children in Central and Eastern Europe and the Former Soviet Union", New York: UNICEF, 1999; Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003); Amnesty International, "Bulgaria - Far from the eyes of society Systematic discrimination against people with mental disabilities", (Washington D.C.: Amnesty International, 2002).

Nevertheless, such good practices demonstrate the feasibility of community-based and inclusive services in the region, and contribute to sensitisation of professionals, users and decision makers to holistic approaches to disability. To build an enabling system, beyond sustaining the existing initiatives and disseminating new services, there is a need to develop and implement coherent national strategies, based on the holistic disability paradigm. This should be a shared responsibility among various stakeholders.

III. ACHIEVING THE CHANGE: KEY STEPS AND SHARED RESPONSIBILITIES

The transitional context of South East Europe creates a great opportunity for change. However, limited resources and the challenging move towards a market economy means that changing the care system and mainstreaming disability will be a long process. There is a need to adopt a **twin track approach** within the change process which has to include long-term reform, inclusion and **mainstreaming of disability. Special programmes and services** that will ensure the sustainable livelihood and conditions for people with disabilities to live with dignity during and after the transition should be developed.

Towards an enabling system

This section of the report outlines the key steps needed to shift the disability paradigm and support the development of an enabling system in the region stressing the **shared responsibilities between stakeholders** involved in the reform and transition processes in the region. As mentioned above, there are many reforms that must be implemented in order to achieve the change. Some of them are preconditions that could stimulate the whole process, such as:

- Acknowledgement that the change process is a shared responsibility between all stakeholders in the region including the state, local civil society and the international community,
- Changing perceptions of disability among the population, starting with people with disabilities themselves, their families and professionals,
- The implementation of progressive legal frameworks initiating long-term change preventing discrimination and promoting equalisation of opportunities,
- Redirecting resources to community-based services and reforming gate-keeping mechanisms,
- The development and implementation of a National Disability Strategy that encompasses all reforms that impact the lives of people with disabilities and the empowerment of a National Council on Disability.

The report does not pretend to tackle all the preconditions needed but highlights the ones that have been identified as important in the field activities of the team conducting the research.

The different stakeholders in the transition

The state

States in South East Europe are all facing similar challenges in the move towards an enabling system for people with disabilities:

- A painful transition severely limiting the states' resources to invest in the reforms,
- A growing number of vulnerable populations not adequately covered by the social welfare system, including people with disabilities, which causes high levels of frustration amongst the population,
- Political instability due to fragmentation of the political movements and the difficulty building sustainable alliances necessary to implement reforms,
- Decentralisation processes with a shortage of resources and unclear distribution of responsibilities,
- Emergence of civil society with the necessary evolution of governance,
- The lack of comprehensive strategies on disability.

Thanks to awareness campaigns and advocacy activities of civil society most governments begin to consider disability as an important issue. Nevertheless, disability is still not a priority for most of the states that are facing the challenge of the economic transition.

Local civil society

While civil society in general still has not mainstreamed disability in their activities, especially human rights organisations, the disability movement remains fragile. In most countries, conflict between DPOs decreases the impact of advocacy. There is a need to build a unified voice that fosters the human rights approach and promotes cross-disability issues while respecting the diversity of interest represented in the disability movement.

International community

Due to the post conflict situation and the EU accession perspective in South East Europe, international actors such as the UN, the World Bank, the EU and INGOs play a key role in reform process because of their capacity to leverage governments as well as their inputs in terms of human and financial resources. They also play an ideological role in introducing modern global values. In the disability field they intend to mobilise policy makers, civil society and states around a new way of thinking about disability based on international standards and instruments such as the UN Standard Rules, ICF and the DCP. Even though they have the responsibility to support states in the de-institutionalisation process to developing a community-based system, their role is partially limited by the following factors:

- Disability is rarely mainstreamed into development programmes across all sectors,
- International actors continue to place disability into disability-specific initiatives rather than viewing disability as a human rights issue and a part of the overall development agenda.

Changing perceptions of disability

An effective enabling system can contribute to inclusion and participation of people with disability only if there is a change in the perception of disability at society level. These changes are not a pre-requisite to any one reform, but should accompany all reforms. The more the change progresses and people with disabilities become visible, the more perceptions will change. However specific activities facilitating this change should be implemented. Three key steps are needed to shift representations and perceptions:

- Awareness raising among people with disabilities themselves, their families, and communities, policy makers, media, and professionals,
- Information and communication on disability issues to increase the knowledge of stakeholders, to make informed changes in policy, and increase awareness of people with disabilities of their rights,
- Training of professionals in the holistic approach to disability. Professionals of ordinary services should develop proper knowledge and attitude regarding disability while professionals working in the field of disability should develop their abilities to support inclusion and independent living of people with disabilities.

DPOs should be the main drivers of initiatives aimed at changing the perceptions of people with disabilities. There are many examples in the region including **Polio Plus'** awareness raising campaigns in Macedonia, the **Centres for Independent Living in Bulgaria and Serbia** with their various research initiatives on disability issues.

Comprehensive and anti-discrimination legislation

In order to ensure the impact of an evolution of the care system, states have to implement anti-discrimination legislation that makes comprehensive changes in legal frameworks. These changes in legislation should include strong enforcement mechanisms and monitoring by a disability council at the governmental level. Primarily addressing civil rights of people with disabilities, anti-discrimination acts bring leverage for comprehensive change. One of the main types of discrimination is related to the freedom of movement. States need to take action to make the built environment, as well as communication and information accessible to people with disabilities. Providing tools to fight discrimination will enable people with disabilities to be recognised as part of society. It is a strong lever for comprehensive change by bringing more visibility to these citizens and the barriers they are facing.

Besides these anti-discrimination tools, states should develop transitory incentive measure as affirmative actions that support the implementation of anti-discrimination such as enforcing quotas, support to employers of people with disabilities, and adapted income maintenance that are not a disincentive for

people with disabilities trying to enter the regular work force.

These two key steps allow for immediate changes during the transition to an enabling system. Examples in the region are limited to a special anti-discrimination law currently being drafted in Serbia by legal experts on disability and anti-discrimination in collaboration with the Ministry of Labour, Employment and Social Affairs. There are many examples in the region of accessibility initiatives including the international annual *Access conference*.

Redirecting resources

Community-based services prove to have an enabling impact on the lives of people with disabilities. Therefore, an essential part of reforming the care system is orienting a country's financial and administrative resources towards community-based approaches and supportive social security measures that are not a disincentive to inclusion. The high cost of transition and the prioritisation that it implies makes it critical for states to operate the change especially as community-based service provision proves to be more cost-effective⁷.

Redirecting resources is a reorganisation of state finances, to change the flow of finance towards an enabling system based on purchaser and provider and supportive social security measures that are not disincentive to inclusion. It involves changing the management structures inside the care system to allow people with disabilities to exercise their rights by creating efficient regulatory systems to manage the decentralisation of services so that the service delivery is based around needs based assessments directing the beneficiaries to the appropriate services. Furthermore, building financial incentives for quality services that are evaluated on effective delivery of service and include users in the development of quality practice is a critical stake in the change process. Some of the main reform mechanisms that need to be implemented in order to redirect resources include:

- **Gate-keeping** - redefining assessment processes towards a needs-based approach,
- **Quality standards, accreditation and licensing** - a way of sustaining community-based services and improving the quality of services,
- **Pension reform** - there is a need for a proper income maintenance system but this is a long-term process - in the meantime, disability pension is the only form of income for people with disabilities who do not have the possibility to obtain employment.

Gate-keeping

Gate-keeping sets the analytic framework for defining the decision making that guides efficient and effective targeting of services. Currently in the region, gate-keeping mechanisms are based on a very medical approach categorising people by type of impairment

⁷ David Tobis, "Moving from Residential Institutions to Community-based Services in Central and Eastern Europe and the Soviet Union", Washington DC: World Bank, 1998: 37.

rather than according the needs of people with disabilities. Moreover the weakness of mechanisms for reviewing decisions prevents the care system from adapting to the evolving needs of people with disabilities. In addition it has been shown that the current systems are not transparent, allowing corruption and irrelevant use of available resources.

A system based on proper needs assessments should allow better cost effectiveness of service provision for people with disabilities as well as a higher level in transparency. It can be a strong mechanism to influence the change of the whole care system by diverting clients from institutional care and promoting further development of community services more adapted to assessed needs. One of the few examples in the region is the reform of the Commissions for Categorisation in Serbia, not yet adopted by the Government.

The need for quality standards, licensing and accreditation

Many community-based initiatives are struggling to survive due to the non-existence of proper mechanisms of public funding. Mainly, funding is project-based, jeopardising the organisational development of the service providers that must to some extent focus on the survival of their structures as well as on the quality of service delivery. Moreover, there is no consistency in the type of services delivered. For instance the name 'Day Care centre' covers very different types of structures and delivering services in a very different way. Thus, implementating quality standards of services, paving the way for licensing and accreditation procedures is a critical stake in the reform processes. Standards that ensure equitable and efficient services that are targeted to meet individuals' needs have to be created. Formal licensing and accreditation processes are also a critical part of redirecting financial resources to local service providers, which will be accompanied by the decentralisation process in South East Europe. One of the few examples in the region is the process of adopting quality standards in Romania instigated by NGOs and the licensing of the service of Independent Living homes provided by the Association for Promoting Inclusion in Croatia.

Pension reform

As any country that is in transition, the states in the region have to adapt their pension systems to face the challenge of long-term economical viability. Because there is no income maintenance system in place for people with disabilities, disability pension is one of the only forms of income for people who are unable to work due to the multiple barriers they face entering the labour force. Under the former system, they were based on benefits given according to categories of disability or according to the type of disability one had, not on one's needs. Therefore, the pension system needs to be reformed so that benefits are based on one's needs and resources should be redirected to ensure more equity.

Examples in the region include disability pension reform initiatives in Bosnia and Herzegovina and Serbia. These reform initiatives consist in tightening eligibility criteria, but in most cases without adopting comprehensive needs based assessment mechanisms, and with still a disincentive effect on professional inclusion.

Moving forward: the need for a National Disability Strategy and National Council on Disability

To ensure an effective implementation, all the reforms impacting disability need to be placed in a **National Disability Strategy**. These strategies should be comprehensive and cross-cutting, and involve people with disabilities and DPOs in the planning and implementation processes. A National Disability Strategy should be built using strong research and situational analyses so that it becomes a tool that guarantees the mainstreaming of disability in PRSP implementation and EU accession. Tools exist to support stakeholders in the definition of these strategies, such as *Agenda 22*. In the region, Albania and Croatia each recently adopted a National Disability Strategy.

To design and implement these strategies as well as to ensure proper consultation with people with disabilities, **National Councils on Disability** must be created. At the very least, they should be composed of representatives of people with disabilities and relevant ministries and public authorities. They should reflect the diversity of the disability movement in order to ensure proper representation of people with disabilities.

CONCLUSION

During 12 years of activities in South East Europe, Handicap International has been supporting people with disabilities, care system professionals both in residential institutions and in community-based services, as well as policy makers in their effort to improve the living conditions of people with disabilities. As shown in this report, Handicap International is witness to numerous valuable initiatives throughout the region that are currently struggling to survive. Both the lack of political will and comprehensive policies in the region in addition to a global misunderstanding of disability issues undermine the change process towards an enabling system aimed at an equalisation of opportunities and full participation of people with disabilities.

Policy-makers and decision-makers, as well as most professionals, are trapped in a medical approach to disability and thus in an institutionalised way of providing services. Implementing a shift of paradigm now would save time and resources in the long run while having a very positive impact on the lives of people with disabilities. For instance, the development

of inclusive education should become a priority for all states, as it could bring a change in the perception of disability for future generations. The adoption of strong anti-discrimination legislation and the enforcement of accessibility rules and regulations could also bring tremendous change in the way societies view disability.

Considering the current favourable political momentum for reform and after years of crises that have endangered the rights and dignity of people with disabilities, the time for change has come.

Building an enabling system, promoting the equalisation of opportunities and removing barriers to participation of people with disabilities is becoming an acknowledged duty for the states, notably through the current elaboration of the UN international convention for the enjoyment of human rights by people with disabilities. Nowadays, the main question for states and other stakeholders involved should not be about fulfilling this duty or not, but how to move forward.

GLOSSARY

Accreditation*

Accreditation is a voluntary process that offers service providers recognition for obtaining standards of excellence defined by an accreditations agency.

**As defined by Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003)*

Care System

Overall system of medical, social, education and employment services that are designed to answer the needs of citizens. In this report is considered mainly the way the care system answers the needs of people with disabilities.

- An **institutionalised care system** for people with disabilities is a system of medical, social, educational, employment and other support services that is designed with the aim to protect them, and in which the control of the services and thus of the lifestyle is ensured mostly by the professional experts in specialised institutions.
- An **enabling system** is a system of services oriented towards supporting people with disabilities to reach and maintain their optimal level of independence and social participation. This goal is achieved through ensuring them an equal access to mainstream services existing at the community level (ordinary medical, social, education, and employment services), with individualised support services according to each one's needs and expectations, and referral to specialised services when needed.

Community

Close environment of an individual including the population and all different stakeholders (public or private), on a confined geographical area, who share feeling of common belonging and experiment common constraints.

Community-Based Rehabilitation (CBR)*

CBR is a strategy within general community development for rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.

**As defined by ILO, UNESCO, UNICEF and WHO Joint Position Paper on CBR; 1994*

Community-Based Services (CBS)

Services provided at the community level and organised in partnership with or by the members of the community with the involvement of beneficiaries in the prioritisation of the needs, the planning and the evaluation of services.

Day Care Centre

In this report Day Care centres refer to the development of structures that provide services such as education, (re)habilitation, leisure activities for children or adults with disabilities in the local community. They developed due to the lack of access to mainstreamed services for this group of persons to fill the gap, either as an alternative or as a complement. The specificity of these Day Care centres is the interdisciplinary team approach and the complex chain of services that is in contrast to the traditional specialised institutions.

De-institutionalisation

The process by which a care system, originally aiming to protect people with disabilities by excluding them from society, transforms into a care system that aims to facilitate social participation by offering a wide range

of services provided at community level, and respects the principle of choice and decision. The concept of de-institutionalisation must thus be differentiated from the notion of "transformation of residential institutions", which is the process of reforming those institutions' mandate and the services they provide.

Disability

In this report, the authors refer to the definition given in the Disability Creation Process model : Disability is a disturbance in a person's life habits as a result of a dynamic interaction between personal factors (impairment or disability) and environmental factors (obstacles).

Disability Movement

In the present report the disability movement is defined, primarily, as the group of all organisations of people with disabilities and individuals at the local, national or international level. In a broader perspective, it encompasses as well, the other stakeholders and their allies in promoting the rights of people with disabilities in agreement with the principle of leadership of people with disabilities themselves within the movement.

Disability Paradigms

The notion of disability paradigm refers to a set of assumptions, values, concepts, and practices that constitutes a way of thinking and talking about disability, within a society and notably among decision-makers, professionals and persons with disabilities themselves. In this report, the authors refer to 3 main disability paradigms:

- The medical model views disability as an individual pathology, to be cured or rehabilitated by medical specialists.
- The social model considers that disability is the result of social barriers (of various kinds such as discrimination, negative attitudes, inaccessible physical and social environment...) that prevent people with disabilities from participating into the society. The answer lies in antidiscrimination actions and removal of barriers.
- Holistic models try to bring about a global understanding of disability, taking into consideration personal and environmental factors. According to this approach, comprehensive answers should be brought in various sectors to allow an equalisation of opportunities for persons with disabilities. The Disability Creation Process is one of those holistic models (refer to Part 1, Box 4)

Disabled People Organisation (DPO)

A term commonly used to consider organisations of people with disabilities. The main characteristic of DPO's is that the leaders of the organisations (in the "driving seat" of the organisation) have to be people with disabilities. In addition, the organisations' mission should be oriented toward the representation of people with disabilities and the promotion of their rights.

Empowerment

The empowerment of a group or community is an increase in its strengths and improvement in its capacity to accomplish its goals. The empowerment of a group leads to the development of its capacity to influence the decisions and policies that have impact on the lives of its members.

Environment

The environment is the sum of all the physical or social dimensions that determine a society's organisation and context.

Equalisation of Opportunities*

The term "equalisation of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities.

- The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.
- Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.
- As persons with disabilities achieve equal rights, they should also have equal obligations. As those rights are being achieved, societies should raise their expectations of persons with disabilities. As part of the process of equal opportunities, provision should be made to assist persons with disabilities to assume their full responsibility as members of society.

* As defined in the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Introduction

Gate-keeping*

Gate-keeping is the system of decision-making that guides effective and efficient targeting of services for people with disabilities or other vulnerable groups.

** As defined by Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003)*

Governance (care system governance)

Governance, as defined by the UNDP, is the exercise of economic, political and administrative authority to manage a country's affairs at all levels. Good governance is, among other things, participatory, transparent and accountable*. Care system governance is the exercise of economic, political and administrative authority to manage a country's care system at all levels. Good care system governance ensures public resources, services, standards, policies and legislation are directed towards an enabling system for vulnerable populations, including people with disabilities. It is transparent, accountable, effective and equitable and is aimed at empowering individuals. It has to include people with disabilities in the definition, implementation and evaluation of the policies related to this care system.

** Based on the UNDP definition for governance underpinned by the Universal Declaration of Human Rights.*

Inclusive Education*

Inclusive education, as defined by UNESCO, is a system of education in which all the pupils with special educational needs are enrolled in ordinary classes in their district schools, and are provided with support services and an education based on their forces and needs.

** As defined by UNESCO available at: http://portal.unesco.org/education/en/ev.php-URL_ID=7499&URL_DO=DO_TOPIC&URL_SECTION=201.html*

Integrated Education

In this report we define integrated education as the situation where special classes for children with disabilities are attached and functioning parallel to the ordinary classes within a school.

Institution

Public or private structure with a permanent mandate defined by the state at a central or local level, which provides different kinds of services such as, social, medical, educational, employment.

Interdisciplinary Approach

An interdisciplinary approach implies an exchange of knowledge, analysis and methods between two or several disciplines, through interactions and a mutual enrichment between specialists from various disciplines. From the viewpoint of services provision, it implies coordinated needs' assessment, planning, provision and evaluation of services between specialists from various professional fields, with the aim to better answer the needs of clients/beneficiaries.

Licensing*

Licensing is a mandatory process by which the government grants permission to be a service provider after finding that the service provider has obtained a certain degree of competency required. It ensures that service providers such as social workers have obtained the minimum level of standards to provide certain services.

** As defined by Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003)*

Mainstreaming

Mainstreaming disability is the process by which the state and the community ensures that people with disabilities can fully participate and been supported to do so within any type of ordinary structures and services such as education, health, employment and social services. It implies that disability is taken into consideration in all sectors' legislation and reforms.

Participation (full participation)

The principle of full participation is defined as the possibility for people with disabilities to take part in all aspects of life including decision-making processes, in equal manners. Equal opportunities are integral to achieving full participation of all individuals.

Participatory Process

A participatory process is defined as processes in which involves relevant stakeholders in the policy making or planning, each stakeholder contributing to the end result, having a stake in the outcome and a role in the monitoring and implementation of the final output. A participatory process allows for consultation of all stakeholders involved and should be representative of the different actors.

Quality Standards*

Quality standards provide a set of criteria that can be used to monitor the management and provision of services, the quality of services as well as their outcome. They ensure equitable and transparent transfer or delivery of services to the beneficiary.

**As defined by Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003)*

Rehabilitation*

Rehabilitation is a comprehensive process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. It may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.

** As defined in the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Introduction*

Residential Institution

Public or private structure providing accommodation service often combined with social, medical or educational services.

Resource Centre

A structure providing a source of aid or support that may be drawn upon when needed: "the local library is a valuable resource".

Service

Service is defined as a response to a specific or a broad range of needs of users. The services provided can be free of charge or can be sold (including partial cost recovery system).

Two broad ways of organising services for a specific group of users can be distinguished:

- Specialised services are specifically dedicated for a target population of clients / beneficiaries with homogeneous needs, with the aim to provide them with a precise answer to their specific needs.
- Inclusive services aim at ensuring that the needs of the broader number of clients / beneficiaries can be met within the mainstream system of services, notably through training and sensitisation of professionals and individualised support adapted to each one's needs. Whenever possible, it is assumed that inclusive services allow better social integration of clients / beneficiaries with special needs.

Service Provider

Public structure (institution owned by the state or mandated by the state), private profit making or non-profit making structure (institution, company, NGO) or individual providing a service answering the needs of a beneficiary or a client.

Universal Design*

"Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities."

** As defined by Ron Mace, Center for Universal Design, NC State University, North Carolina, 1997*

PART I

SHIFTING THE DISABILITY PARADIGM TOWARDS FULL PARTICIPATION



PART I

SHIFTING THE DISABILITY PARADIGM TOWARDS FULL PARTICIPATION

Equal opportunities and full participation of people with disabilities can only be achieved through a radical change in the way various support services are organised. This implies an in-depth change in the social perceptions of disability. The late XXth century saw the creation of the so-called "social model" in which disability is considered to result from social barriers that prevent people with disabilities from participating in society. This model ran contrary to the

"medical model" in which disability is considered as an individual pathology. The medical model had previously underpinned much of service provision for people with disabilities all over the world. This part of the report demonstrates how building an enabling system that supports people with disabilities in reaching and maintaining their optimal level of independence and participation must be based on a shift in the disability paradigm towards a holistic approach.

BOX 1

Typology of different approaches and their intervention methods (Rioux, 1977)

DISABILITY viewed as INDIVIDUAL PATHOLOGY

Biomedical origin (biomedical approach)

Treatment Recovery through medical or technological means

Prevention Biological or genetic intervention
Pre-natal detection

Social responsibility Eliminate or cure the disability

Functional origin (functional approach)

Treatment Functional rehabilitation services

Prevention Early diagnosis and treatment

Social responsibility Improve and obtain comfort

DISABILITY considered as SOCIAL PATHOLOGY

Environmental services and factors environmental approach)

Treatment Accessibility, adaptation
Increased individual control over services and support

Prevention Elimination of social, economic and physical barriers

Social responsibility Elimination of obstacles to integration

Social organization and relationship of the individual to society (human rights approach)

Treatment Reformulation of political, economic and social rules

Prevention Acknowledgement that disability is an inherent part of society

Social responsibility Reduce inequalities of rights
Access to full citizenship

1. EVOLUTION OF APPROACHES TO DISABILITY TOWARDS RIGHTS AND PARTICIPATION

1.1. Towards a holistic approach to disability

The cause of disability: individual or social?

Various conceptual models underlie the social perceptions of disability and thus guide the interventions proposed to deal with the "problem". Schematically, two main approaches that oppose one another exist: the medical model and the social model. The issue of causality is at the very core of the difference between the two. The **medical model** views disability as an **individual pathology**, whilst the **social model** asserts the **social origin** of disability. There are two distinct variants of the medical / individual model: the **biomedical model** refers to a curative approach, whilst the **functional model** that helped bring about the development of medical rehabilitation in the mid-XXth century focuses on the functional consequences. The social model, developed over the last 30 years includes an **environmental approach** that focuses on the impact of environmental factors on social participation; and another more socio-political approach, based on **human rights**, focusing on discrimination against people with disabilities. Each of those 4 models proposes different approaches to intervene, prevent disability, and to determine the level of social responsibility (Box 1). The underlying approach determines social attitudes and the place of people with disabilities within society, thus establishing a paradigm through which society and the care system govern disability (Jean François Ravaud⁸, Box 2).

The Independent Living Movement: for a self-determined life

Within the social paradigm, organisations of people with disabilities in various countries have founded a movement (and philosophy) aiming at ending the enforced dependence of people with disabilities on non-disabled people. This movement, called "Independent Living" or more accurately "Self-determined Living" arose during the 1970s. Self-determined / Independent Living does not mean people with disabilities living alone, or doing everything by themselves. It is about finding ways for people with disabilities to control their own lives, fulfil their potential, be empowered, and be included in the rest of the community. Its four key principles emphasise the notions of rights and personal control (Box 3).

Holistic models supporting the development of an enabling system

The social model has undoubtedly brought essential learning values to understanding disability and influenced various inclusive policies. However, one should avoid any type of reductionism, be it medical or social. A positive societal change must be underpinned by a global understanding of disability, taking into consideration all dimensions of the issue. The **Disability Creation Process** (DCP) is a model that seeks to reconcile these two trains of thought using an interactive approach (Box 4). In addition to individual and environmental factors, it also includes a third dimension, the subjective judgement of the situation of disability, which was seldom considered

BOX 2

Disability paradigms determine the place of people with disabilities within a society (Ravaud, 2001)

"The functional or bio-medical model views the person with disabilities as a defective being restricted in his / her ability to carry out his / her social roles. In the social model, the person with disability is described as in a situation of dependency on specialists, institutions and policies. In the first case, the problem lies at individual level and within the theoretical domain of personal tragedy. In the second, it lies on environmental factors, on the social and political context, within the theoretical domain of social oppression. The solution should be looked for in a mutual way, the breaking down of barriers, control by users rather than by the specialists, etc. The social role is no longer the role of "patient" but of "user-consumer". Skills are no longer the domain of experts alone: they integrate the experience of the people concerned. Unlike under the functional model, the anticipated result is no longer to acquire the widest possible physical or psychic independence, to reduce the disabilities with employment or institutionalisation being the only perspectives. Quite the opposite - the social model aims at living independently, with employment a possibility as well as organised assistance controlled by the user".

⁸ Jean François Ravaud, "Vers un Modèle Social du Handicap : L'influence des Organisations Internationales et des Mouvements de Personnes Handicapées," in Cahiers Médico-sociaux, Ed. Raphaël de Riedmatten, (Genève : Editions Médecine et Hygiène, 2001): 55-68.

BOX 3**The Independent / Self-Determined Living Movement is based on four main principles:**

- **Choices and decisions:** people with disabilities should make their own choices and decisions about what affects them (and participate in the choice their family makes),
- **Control:** people with disabilities must have control over their own life (to the same extent as non-disabled),
- **Rights and responsibilities:** People with disabilities have the same rights as non-disabled people, but must as well take responsibility for themselves, their decisions, their actions, ...etc,
- **Freedom to fail:** People with disabilities should have the freedom to fail. We all fail and make mistakes sometimes; this gives us the opportunity to learn and then to try again. Often, however, people with disabilities are over-protected and are not allowed to take risks or even to tackle the most ordinary task. Or if they try and fail, the failure is automatically seen as a result of their impairment, not as a normal part of learning.

Source: Alison Harris, Sue Enfield, *Disability, Equality and Human Rights: A Training Manual for Development and Humanitarian Organisations*, (Oxford: Oxfam UK, 2003).

previously. This judgement is specific to each individual's background and is based on perceived gaps between expectations and achievements. It therefore has a significant impact on the quality of life. For example, hearing loss does not have the same "value" for someone whose main hobby is literature as for a music enthusiast.

The strength of this model lies in the promotion of positive concepts and full recognition of the inputs from the various approaches and their representatives (medical and rehabilitation professionals, users and services providers) and of the various dimensions of disability. It is thus a very interesting tool for:

- Raising awareness on disability,
- Developing comprehensive information systems and research on disability,
- Helping in developing policies and strategies and mainstreaming disability in various service sectors,
- It furnishes tools for professionals to provide interdisciplinary and individualised services for people with disabilities, based on the principles of choice and self-determination.

The recent adoption in 2001 of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organisation⁹, accounts for this shift in disability paradigm among health professionals. Revising the former International Classification of Impairments, Disabilities, and Handicaps (ICIDH), the ICF integrates the notions of participation and environmental factors. Despite its complexity and the fact that it does not clarify the nature of interactions between various factors, the ICF is being used by a growing number of professionals in the field of disability to provide comprehensive

support services.

The shift in disability paradigm that occurred over the past few decades is also shown beneath the evolution of international legislation on disability rights.

1.2 International legal instruments

Disability: a human rights issue

Historically, disability has been dealt with as a legal issue mainly in terms of social security or health legislation. People with disabilities were recognised not as subjects with legal rights but as objects of welfare and charity programs. As a result, this type of social policy segregated and excluded them from mainstream society. Lately however, lobbying by the disability movement contributed to the inclusion of the disability issue within the human rights movement. "With the paradigm shift from the medical to the social model, disability was reclassified as a human rights issue under international law. Reforms in this area were intended to provide equal opportunities for people with disabilities and to expose their segregation, institutionalisation and exclusion as typical forms of disability-based discrimination¹⁰".

Legally binding international treaties

All legally binding international human rights treaties protect the human rights of all human beings including people with disabilities. This is the case of the *Universal Declaration of Human Rights* that states that "...everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex or other status¹¹". The *Convention on the Rights of the Child*¹² and the

⁹ The World Health Organisation International Classification of Functioning, Disability and Health (ICF) available at: <http://www.who.int/classifications/icf/en/>.

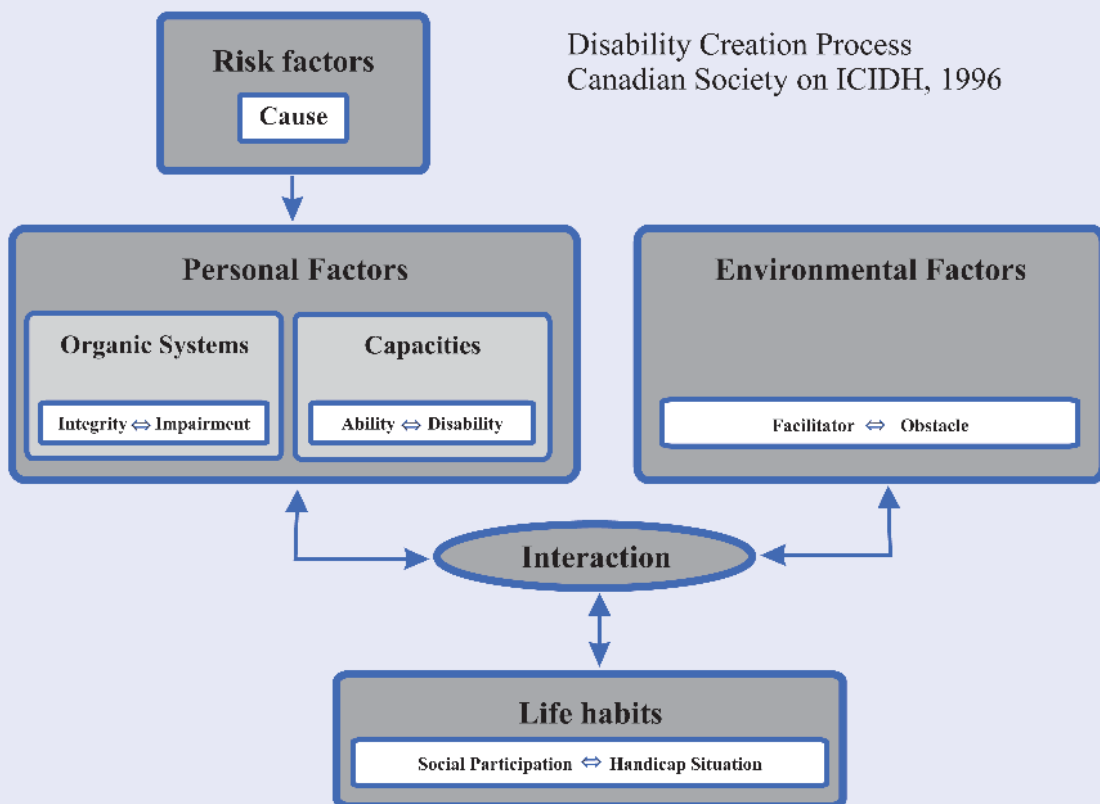
¹⁰ Theresia Degener, Gerard Quinn, "A Survey on International, Comparative and Regional Disability Law Reform," Disability Rights and Education Defence Fund (DREDF), Available at: http://www.dredf.org/international/degener_quinn.html (2000).

¹¹ Universal Declaration of Human Rights adopted and proclaimed by General Assembly resolution 217 A (III) on 10 December 1948, article 2.

¹² Adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 on 20 November 1989, entered into force 2 September 1990.

BOX 4**The Disability Creation Process**

The Disability Creation Process (DCP) adopts a very comprehensive approach to disability. It defines the disability (*handicap situation*) as a disturbance in a person's life habits resulting from a dynamic interaction between personal factors (*impairment or disability*) and environmental factors (*obstacles*). Disability is therefore not a fixed state, but a dynamic process that varies according to the context and environment. According to this model, several types of actions can be undertaken to modify these interactions and achieve social participation: reducing impairment (*medical care*), developing capabilities (*rehabilitation*), as well as adapting the environment (*elimination of physical obstacles, anti-discrimination and accessibility policies*).



Source: P. Fougeyrollas, et al. "The Quebec Classification: Disability Creation Process," (Quebec: INDCP/CSICIDH,

Council of Europe Social Charter¹³ similarly include people with disabilities.

Non-binding international instruments

In addition, there are a number of non-binding international instruments (such as declarations, resolutions, rules or guidelines) that express generally accepted principles and represent a moral and political commitment by states. The 1970s saw the introduction of a series of United Nations (UN) declarations, on human rights and the rights of people with disability. These included the *Declaration on the Rights of Mentally Disabled Persons* in 1971 and

the *Declaration on the Rights of Disabled Persons* in 1975, encompassing the right to human dignity, equal treatment and services and self-reliance.

Of particular importance are the *UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Their adoption by the UN General Assembly in 1993 revealed a large paradigm shift in the perception of the rights of people with disabilities within international law. Instead of viewing disability rights as a special needs issue, this document presents them as an issue of equal opportunities. The principle of equal rights underpins the UN Standard

¹³ Open for signature by the members of the Council of Europe, in Turin, on 18 October 1961, entered into force 26 February 1965, revised in May 1996.

"A coherent and global policy in favour of people with disabilities or who are in danger of acquiring them, should aim at: preventing or eliminating disablement and alleviating its consequences; guaranteeing full and active participation in community life; helping them to lead independent lives according to their own wishes."

Council of Europe Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities - Part 1 (General Policy)

Rules, recommending states to adopt measures for full participation and equality of people with disabilities¹⁴.

Another major reference for the countries of South East Europe that are all, at various degrees of advancement, involved in a process of association with the European Union, is the *Council of Europe Recommendation No. R (92) 6 of the Committee of Ministers to Member States on a Coherent Policy for People with Disabilities*¹⁵. This Recommendation outlines important policy recommendations for member states to achieve equality for people with

disabilities applying equal opportunities and anti-discrimination legislation in a European context.

Other key international references include various texts such as the *Salamanca Statement on Principles, Policy and Practice in Special Needs Education* (June 1994) and the *Madrid Declaration* (March 2002).

Towards an international convention

A comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities is currently being elaborated. It will be the first binding international law specifically on disability. Following the establishment of an Ad Hoc Committee by the United Nations General Assembly in December 2001, a Working Group issued a draft text that is now under negotiation at the level of the Ad Hoc Committee.

As shown earlier, each disability paradigm determines a particular philosophy of prevention and intervention and thus a particular approach to organisation of services for people with disabilities. Transforming an institutionalised care system into a system oriented towards full participation thus requires a shift in the underlying disability paradigm from a medical to a holistic approach.

¹⁴ UN General Assembly resolution 48/96 on 20 December 1993.

¹⁵ Adopted by the Committee of Ministers on 9 April 1992 at the 474th meeting of the Ministers' Deputies.

2. BEYOND DE-INSTITUTIONALISATION, THE NECESSARY DEVELOPMENT OF AN ENABLING SYSTEM

2.1 Institutionalisation of disability: a medical-based and overprotective care system leading to social exclusion

Originally, institutionalisation was a term used to describe the living arrangements and conditions of people with mental disabilities that were housed in large, state-run institutions¹⁶. Goffman described the consequences of those "total institutions" on the individual as a process of "civil death," leading to loss of control¹⁷.

This definition does not reflect the fact that most of the people with disabilities in an institutionalised care system do not live in residential institutions. Most of those living within a family setting are also denied social, educational and economic opportunities. The definition should thus be broadened to describe **institutionalisation as the overall phenomenon by which an individual with a disability loses control over his / her own life.**

Thus, an "**institutionalised care system**" for people with disabilities is a system of medical, social, educational, employment and other support services that is designed to protect them, and in which the control of services and therefore, lifestyle, is ensured mostly by professional experts in specialised institutions. Such a system results in social exclusion. It has a "**disabling effect**", as it prevents people with disabilities from reaching their full potential in terms of independence and social participation. The causes of institutionalisation are grounded in a **medical and paternalistic approach to disability**, where the person with disability is seen as defective, unable to care for him or herself and is thus in need of 'protection'. Medical professionals are considered to be solely competent to care for people with disabilities.

At each key-period of life, decisions are made by commissions of experts that decide upon the type of education, vocational training, treatment, employment and even housing each individual will have access to. Decisions are based on medical diagnosis and functional status, with little consideration given to environmental factors and individual wishes. Even though decisions may not be compulsory, the absence of alternatives and the low level of information available on rights, services and diagnosis often place the person with

severe disabilities - or their parents - in the position of having to choose between staying homebound or being placed in a residential institution. Only certain persons with mild disability or with strong willpower and family support can achieve an independent life integrated into the community.

2.2 De-institutionalisation: the necessary development of community-based services

Proponents of de-institutionalisation originally advocated for the movement of individuals out of institutions and into the community. Over time, it became clear that this process did not contribute sufficiently to equal participation of people with disabilities in society and that the development of a system of **Community-Based Services (CBS)** should be implemented in parallel to the closure of residential care institutions (Box 5)¹⁸. So the notion of de-institutionalisation should also entail a change in the method of service delivery, away from institutional-based services and towards services provided in a community setting. De-institutionalisation should thus be defined as "**the process by which a care system, originally aiming to protect people with disabilities by excluding them from society, transforms into a system that aims to facilitate social participation by offering a wide range of services provided at community level while respecting the principle of choice and decision**".

Community-based services as presented in this report should be perceived within the conceptual framework of Community Based Rehabilitation (CBR)¹⁹. It is estimated that up to 70% of people with disabilities can receive meaningful (re)habilitation within their communities using this approach. The term CBS rather than CBR, is used in this report since it better describes the wide range of support services that should be provided to people with disabilities to ensure their full participation in society.

2.3 Shifting the disability paradigm in order to move towards an enabling society

The ultimate goal of the de-institutionalisation process should be the establishment of an **enabling system**

¹⁶ According to Tobis, around 4% of people with disabilities in the countries from the former Soviet Union and Central and Eastern Europe were living in residential institutions in 1995, mainly people with mental disabilities in David Tobis, "Moving from Residential Institutions to Community- Based Social Services in Central and Eastern Europe and the Former Soviet Union," (Washington D.C.: World Bank, 2000).

¹⁷ Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, (New York: Penguin, 1961): 5.

¹⁸ Karl Grunenwald, "Close the institutions for Intellectually Disabled," A pamphlet for the European year of People with Disabilities, Stockholm, Sweden (2003).

¹⁹ "CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services." ILO, UNESCO, UNICEF, WHO, Joint Position Paper on "CBR for and with People with Disabilities," (ILO, UNESCO, UNICEF, WHO, 1994).

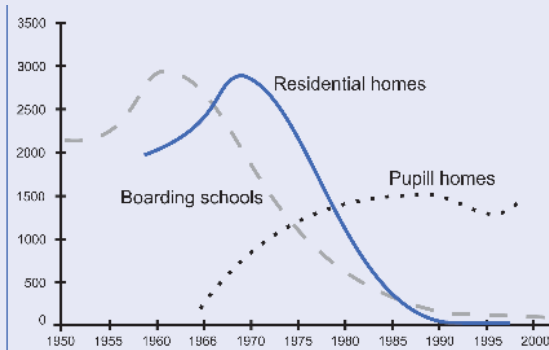
BOX 5

About Sweden's experience of closing residential institutions

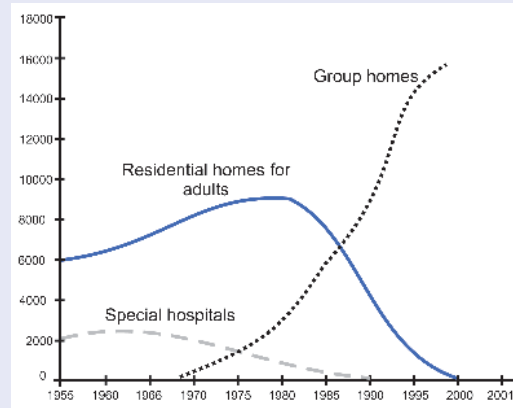
The strategy of dismantling residential care for children in Sweden was initiated by providing education in special classes within the regular education system, thus reducing the reliance on boarding schools. As parents and families of children with disabilities gradually gained access to improved financial and personal support, such as free day-care services, kindergartens and local experts (so called habilitation teams), residential homes could gradually be closed. New types of homes were established for the few parents who could not manage to keep their children at home, and were designed as small group homes of four children open 24 hours a day.

Source: Karl Grunenwald, 2003

Children with intellectual disabilities



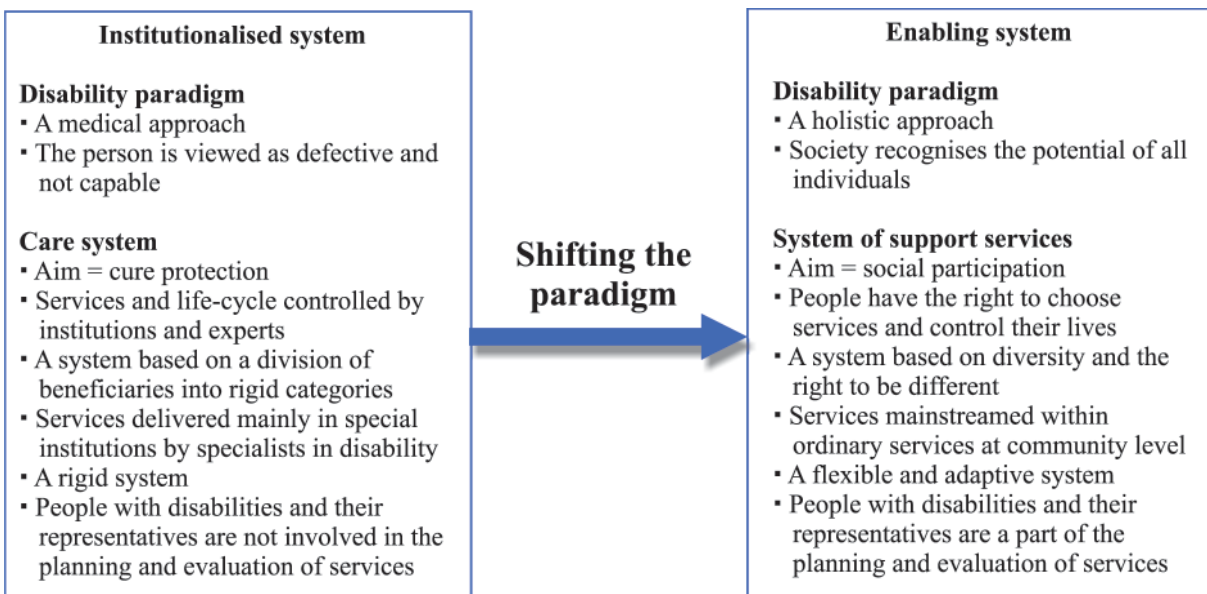
Adults with intellectual disabilities



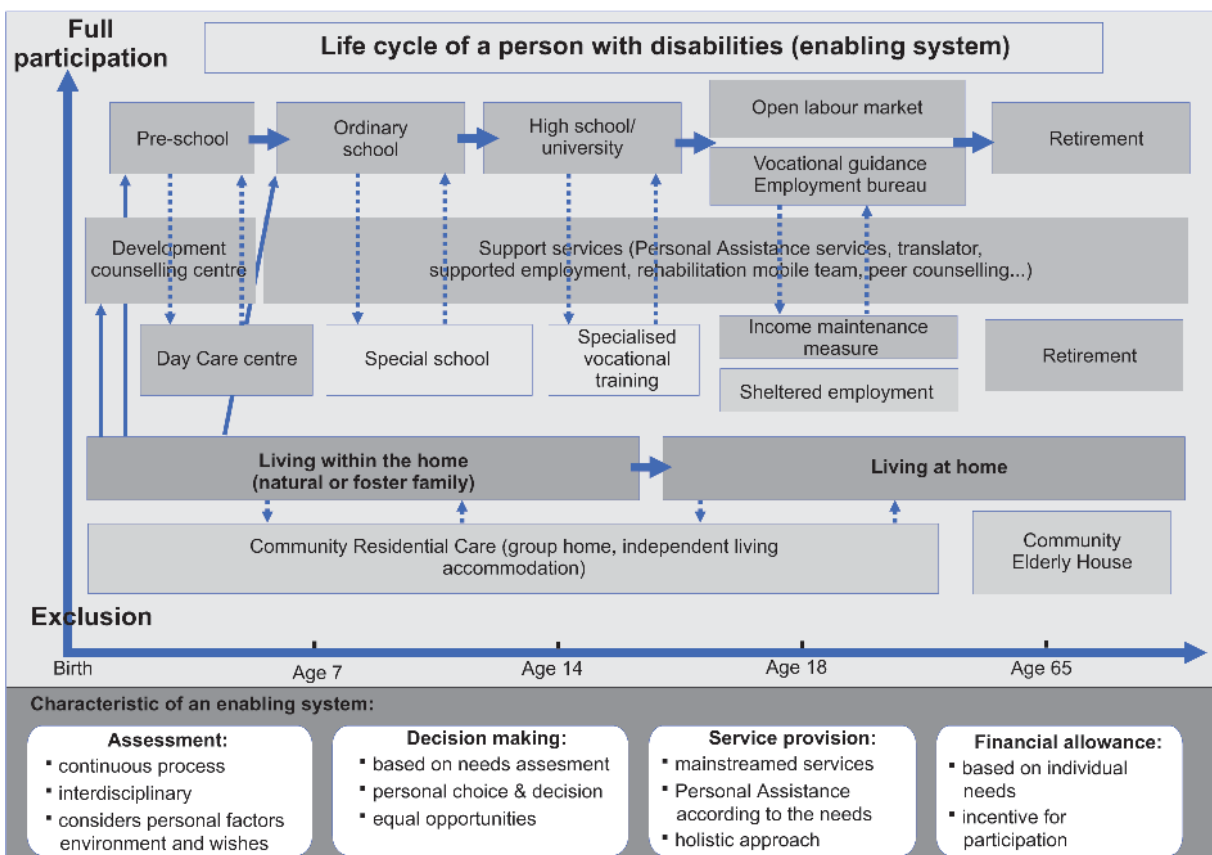
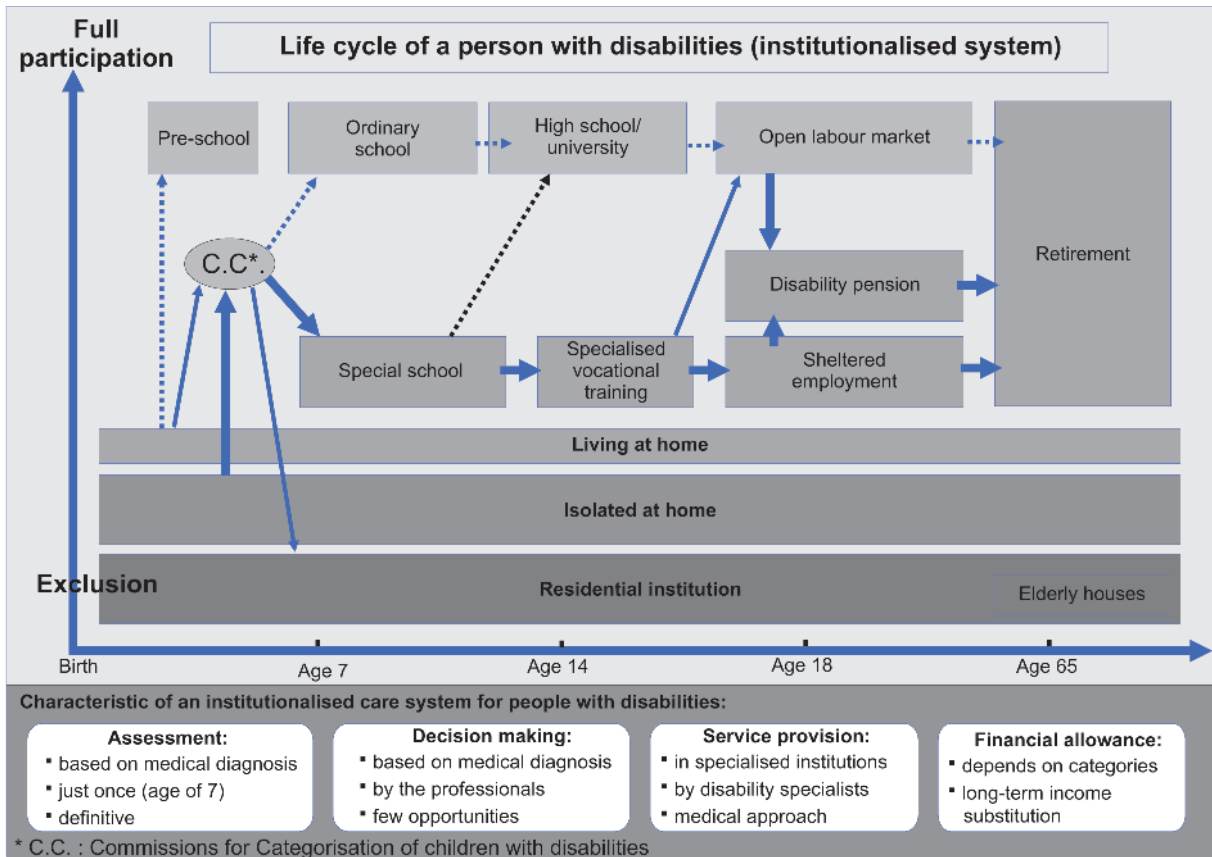
Scheme 2. Shifting the disability paradigm

There is a need to operate an in-depth change in the disability paradigm which determines how people with disabilities are assessed, the types of services they have access to as well as how these services are defined and evaluated. The disability paradigm also

determines how people with disabilities are perceived within society. The scheme below shows the key points of this needed shift in paradigm underpinning the current care system and defining the new priorities under an enabling system.



Scheme 3. Comparison of the typical life cycles of a person born with a disability in an institutionalised care system and in an enabling system








that **gives people with disabilities control over their own lives**. This type of system should be oriented towards supporting people with disabilities in reaching and maintaining their optimal level of independence and social participation, taking into account personal factors, environment and expectations. In such an enabling system, the person is at the centre of the system, and has access to a variety of services that provide the **opportunities and choice for the person to decide** about his/her life-style. An enabling system should include **equal access to mainstream services** existing at the **community level** (ordinary education, health, employment and social services), with **individualised support services** according to individual needs, and referral to specialised services as required. Access to individualised and comprehensive **assessment, information and counselling** should also be guaranteed in order to allow real choice. An

enabling system would also ensure that representatives of people with disabilities "participate in the planning, implementation and evaluation of services (and more generally of measures) concerning the lives of people with disabilities²⁰".

Scheme 3 compares the lifecycles of an individual born with a disability within an institutionalised care system to that of one in an enabling system. It shows within each system how an individual with disability can build his/her lifecycle, and how he/she can be oriented or choose to place him/herself within the system of services and institutions available. The scheme presents two opposed systems, while in reality various types of services often coexist within the same society. All the options could not be represented on each scheme.

Legend for Scheme 3:

-  - Shows the possible routes from one type of institution/ service to another. Thickness accounts for the frequency of each possible route.
-  - Shows an itinerary that is possible but rare or unusual within the system.
-  - Shows the facilitated possibility for a person with disabilities to choose between specialised and mainstream services throughout their life according to their will and needs.

-  Pre-school - Service or institution that exists but is considered as a rare option.
-  Day Care Centre - Common type of service or institution.

²⁰ United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Rule 18 (see Annex 1)

Life story 1: Completing education despite enormous barriers, from Serbia and Montenegro

Ljuba from Belgrade

I was born in 1978 in Belgrade. I am told I suffered a head injury during delivery and hence suffer from cerebral palsy. I spent the first 3 ½ months of my life in an incubator as I was born prematurely. I have been registered with the Institute for Cerebral Palsy in Belgrade since being diagnosed at age 6 months. My parents took very good care of me. My mother made sure I did all of the exercises required for my rehabilitation. She took me for regular exercises at the Institute for Cerebral Palsy as well as other institutions. She worked intensively with me on developing my speech as well as my physical abilities. At age 4 ½ I had just begun to speak but by age 5 I could read both Latin and Cyrillic scripts.

Unlike other children with a disability I didn't have any problems with 'Commissions for Categorisation'. In fact I commenced primary school prior to being assessed by the commission. I did undergo regular school-entry testing like all other children and my results were well above average, so that I had no problems. When I was finally assessed by the commission for categorisation I was 8 years old and it was solely for the purpose of determining my eligibility for 'Care and Assistance by Another Person' payment. Several months after the assessment we were notified that I qualified for this allowance and that no review of this qualification would be conducted in future. I still receive this payment today.

I attended regular classes at St Sava primary school, Belgrade. I had no problems with the children or teachers at school. But then when I was in grade 5 we moved address and by law I had to move schools. That's when I started having problems. I was called disruptive because as the best student, I asked a lot of questions. The teachers complained to my mother, who said that I was no different to any other child and that if I was disruptive I should receive the same punishment as anyone else.

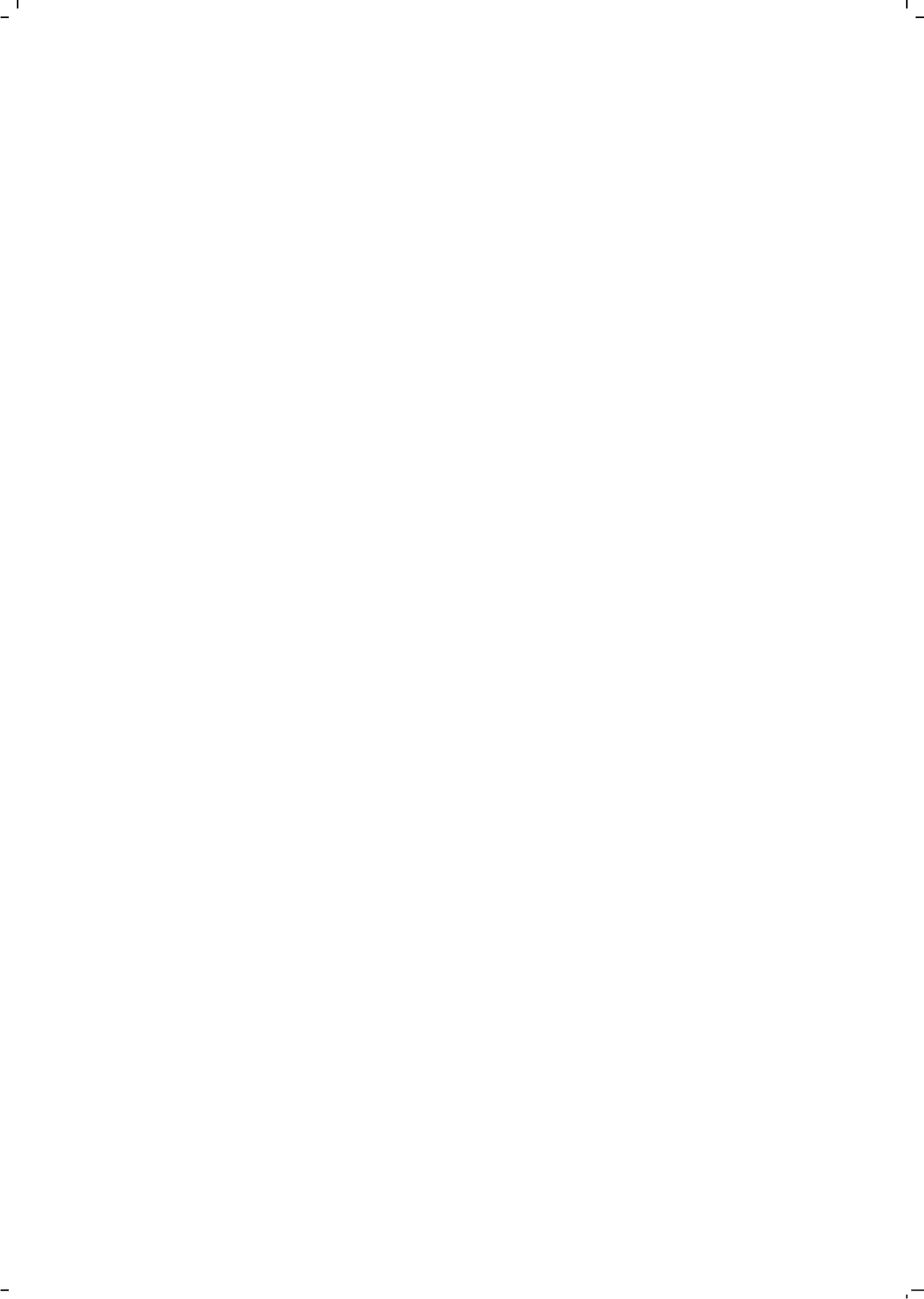
Despite this interruption, I maintained my concentration and finished primary school with perfect grades. I received the 'Vuk Karadzic' award for having full marks for each and every subject in every year. The only subject I didn't attend was physical education.

When the time came to enrol in high school, my mother contacted the local school. The director was impressed with my grades but when he found out I suffered from cerebral palsy he balked at enrolling me. He said that "It is not stated by law that I must accept the enrolment application of a child with disability". My mother argued that I was an excellent student and that I required no special provisions or adjustments but to no avail. She also told him that the real argument was that there was no provision in the law barring me children with disability from enrolling and so he couldn't refuse to consider my enrolment. He wouldn't budge from his position and appeal procedures were either non-existent or so convoluted as to be useless. So on enrolment day itself, my mother went to the school, saw the deputy-principal and explained that I couldn't enrol in person as I was on my summer vacation. The deputy-principal enrolled me on the basis of my primary school results and so I was set to start regular high school!

My high school years were somewhat marred by the refusal of several of my teachers to accept

the fact that I didn't suffer from any form of intellectual disability despite my cerebral palsy. Unfortunately, they tried to stereotype me and when they couldn't, they took it out on me. The worst case was when one teacher spent a whole lesson asking me the most difficult questions while I stood at the front of the class. I went home with a headache and fever, but I refused to be humiliated.

I completed high school with excellent grades and enrolled in the Faculty of History at Belgrade University without having to sit an entrance examination. I am now in the process of applying to do my PhD in history at the same university.



PART II

THE UNSTEADY DEVELOPMENT OF COMMUNITY-BASED SERVICES IN SOUTH EAST EUROPE



PART II

THE UNSTEADY DEVELOPMENT OF COMMUNITY-BASED SERVICES IN SOUTH EAST EUROPE

The "institutionalisation of disability", discussed in the first part of this report, embedded the service provision within the care system towards people with disabilities and their families in South East Europe during the time of the communist regimes. This approach led to the segregation and exclusion of people with disabilities from social and community life, by isolating them either within their own families, or in residential care institutions. This occurred despite the fact that the proclaimed aim of society was to enable people with disabilities to be employed, to live independently, to have material security and to have access to necessary services. People with disabilities, more than others, lacked the most basic of human rights, the opportunity to choose and decide for themselves.

The social welfare system was universal and provided for families in terms of guaranteed jobs, pensions and allowances. The system also provided in-kind benefits such as education and housing as well as health care. Anyone in need of individual support beyond this universal protection was directed towards institutional care where available. Since the needs of people with disabilities are often more specific and require a comprehensive approach to provision of assistance, they fell into the group whose needs could not be fully met by the public system, thus leading to segregation, isolation and institutionalisation. It is widely acknowledged that services provided at community level ensure a better quality of life for the person with disability, as well as being more cost-efficient compared to highly specialized institutions and residential care²¹.

BOX 6

Types of community-based services that should be developed or mainstreamed within ordinary services in an enabling system

- Day Care Centres for children and adults with disabilities,
- Vocational training,
- Supported employment,
- Inclusive education/integrated education,
- Counselling Centres (including peer counselling),
- Personal Assistance services,
- Independent Living Centres/community based residential apartments,
- Adapted transportation systems for people with disabilities and mainstreaming existing transportation,
- Respite care,
- Home visiting services,
- Physical rehabilitation services,
- Foster families and or family group homes,
- Adoption,
- Sheltered workshops / supported employment.

²¹ David Tobis, "Moving from Residential Institutions to Community- Based Social Services in Central and Eastern Europe and the Former Soviet Union" (Washington D.C.: World Bank, 2000); Louise Fox , Ragnar Gotestam, "Redirecting resources to Community-Based Services - A Concept Paper" (Florence: UNICEF Innocenti Centre and the World Bank, 2003).

1. DE-INSTITUTIONALISATION IN SOUTH EAST EUROPE

A process of de-institutionalisation as well as a slow process of de-centralisation of the fiscal system and decision-making processes that started during the 1990s are still being implemented throughout South East Europe²². Accession to the European Union is also a driving factor for these countries, and reforms and policy changes will be directed towards satisfying the criteria for accession (such as in the cases of Romania and Bulgaria).

De-institutionalisation of disability, in terms of provision of services such as social welfare, education, employment and medical health care, has been the major trend in Western Europe and North America since early 1970's. Some countries like Sweden and Norway have progressively closed all large scale residential facilities and developed a system of **Community-Based Alternative Services** provided within primary health care institutions, in family like settings, group homes, and home based care and through personal assistance. These are all pre-conditions for equal participation for people with disabilities. A path towards an enabling system, based on mainstreamed services and universal design, is on the agenda in Western countries, in-line with the demands of the international disability movement. As mentioned, the need for development of new types of services for people with disabilities has been recognised in South East Europe and the change process has been initiated. An analysis of the systems of services available for people with disability in the region reveals the slow and non-cohesive development of a few inclusive, holistic, community-based services, and that the notion of mainstreamed services is still not on the agenda.

1.1 Assessment of community-based services in South East Europe

This section of the report describes the change process in terms of de-institutionalisation and the development of a community-based services system, taking into account the legacy of a protective and exclusive care system as described in the introduction (Box 6). Several examples of good practice and innovation in the provision of enabling services and social welfare are presented, showing real-world implementation of a holistic approach to disability and the main values of inclusion and participation. Indeed, if one puts together all the good practices and initiatives in the various fields currently implemented on a small scale in the region, a picture of an enabling system and a model of society where people with disabilities are included in the

community as are all other citizens, with equal rights and opportunities can be seen. With this goal in mind, it is important that experiences and lessons learned should be shared and disseminated throughout the region.

Good practice: Service providers cited in this report as an example of good practice in the community-based service field have met certain important criteria; ensuring they have a sound sustainability strategy and a workable approach to enabling people with disabilities to participate in their communities. These criteria are based on various existing standards of (re)habilitation and social services²³:

- Social and inclusive approach to service delivery,
- Existence of individual needs assessments, planning and evaluation,
- Interdisciplinary and teamwork approach,
- Involvement of users/families in the service,
- Continuous training for staff,
- Level of partnerships - public/civil society/private,
- Financing and strategies for sustainability,
- Official recognition,
- Accessibility.

All the organisations and institutions selected for this report have been visited and assessed according to the same indicators. This assessment was performed by Handicap International staff with the aid of our partners who provided information when necessary. It is not an exhaustive description of services in the region, rather an overview of change occurring in the region, illustrated with selected examples.

1.2 International standards and recommendations as references for analysis

The logic of the presentation of this section has been divided into six categories: medical care, (re)habilitation, support services, education, vocational training and employment, and the transformation of residential institutional care. The overall references for the description are the **UN Standard Rules on the Equalization of Opportunities for People with Disabilities** (UN Standard Rules)²⁴ and the **Council of Europe Recommendations No. (92) 6 on a coherent policy for people with disabilities** (CoE R)²⁵. We have chosen these instruments because they complement and augment each other, as the UN Standards Rules focus on the rights of persons with disabilities while CoE R is a guideline for policy making.

²² Using the wide definition of 'de-institutionalisation' defined in Part I. section 2.2 of the report.

²³ Aurora Day Care centre, ACSHF-R, NACCP and UNICEF, "Quality standards for Day Care centers in Romania," (Bucharest: 2002); Department of Health Government UK:

National minimum Standards of Residential Family Centres <http://www.dh.gov.uk/assetRoot/04/03/44/12/04034412.pdf>;

National Minimum Standards of children's homes <http://www.dh.gov.uk/assetRoot/04/03/43/19/04034319.pdf>.

²⁴ The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, proclaimed by the UN General Assembly resolution 48/96 of 20 December 1993. Available at: <http://www.un.org/esa/socdev/enable/dissre00.htm>

²⁵ Council of Europe, Recommendation No. R (92) 6 of the Committee of Ministers to Member States on a Coherent policy for people with disabilities. Adopted by the Committee of Ministers on 9 April 1992 at the 474th meeting of the Ministers' Deputies.

2. MEDICAL CARE: THE NEED TO ENSURE EQUAL ACCESS TO PRIMARY HEALTH CARE

UN Standard Rule 2. Medical Care (extracts)

States should ensure the provision of effective medical care to persons with disabilities.

- States should work towards the provision of programs run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects,
- States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

To ensure that people with disabilities have equal access to medical care according to their needs, Primary Health Care (PHC) should play a key role. According to the 1978 Alma Ata Declaration, PHC is presented as essential care that should be made accessible to individuals and families in the community²⁶. It is the first level of contact with the health care system, where most of people's health problems are dealt with, and which provides preventive, curative and rehabilitative care, implying collaboration between various sectors of society. However, specialised medical care still underpins most care provision for persons with disabilities in the region.

2.1 Legacy and current context

Lack of medical rehabilitation services within Primary Health Care

The organisation of the health care system varies in each country of South East Europe, but PHC was extensively developed by all the former regimes through a network of health centres, and it is still supposed to be the compulsory entry point to the health care system. In the former Yugoslavia however, the distinction between the primary and secondary levels was unclear, resulting in a strong focus on the development of specialised care services and hospital care, to the detriment of family medicine and prevention²⁷.

Physical Medicine and Rehabilitation (PMR) services are on average poorly developed within PHC settings in the region, with some notable variations. In all the countries stemming from the former Yugoslavia, health centres should usually provide physiotherapy services, but this is the case mainly in larger municipalities, while rural areas most often lack human resources and equipment. Physiotherapy at the PHC level, where it exists, is mainly oriented towards treatment of orthopaedic and light neurological impairments. In Albania physiotherapy

services do not exist at all the PHC level²⁸. The impact of wars and/or economic crises brought about financial shortages, increased geographical discrepancies and rationing, with rising inequity in access to health services, affecting primarily the poorest.

An over-specialised medical care provision for people with disabilities

This general situation also restricts access to health services for people with disabilities, adding to the legacy of an institutionalised care system that systematically orients people with disabilities towards specialised health institutions (specialised hospitals for rehabilitation), based on type of impairment, to be provided with both rehabilitation services and general medical treatment by disability specialists. This over-specialised system that led to segregated care services implies that the notion of mainstreaming existing health services to be accessible for all citizens is rarely implemented in the region. It is not rare to find health care facilities with inaccessible premises. Many services that are being developed are still designed specifically for people with disabilities, and general health professionals have limited and outdated knowledge on disability issues. Nevertheless, a few encouraging examples of medical services developed at community level can be found in the region.

2.2. Initiatives for change

Developmental Counselling Centres: a multidisciplinary support at community level for children with disabilities

Despite the generally overspecialised medical approach, the former Yugoslavia had also established some alternative medical care settings for children with disabilities over the last two decades: "Developmental Counselling Centres" were established in a number

²⁶ World Health Organisation, "Primary health care - Report of the International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978." Health for All Series, No. 1 (Geneva: 1978).

²⁷ For more information on health care systems in the region, consult: J.Cain and E. Jakubowski, Health Care Systems in Transition: Bosnia and Herzegovina 4(7) (Copenhagen: European Observatory on Health Care Systems, 2002); B. Nuri and E. Tragakes, Health care systems in transition: Albania 4(6) (Copenhagen: European Observatory on Health Care Systems, 2002); and S. Hajioff, G. Pecelj, and F. Tozija, Health Care Systems in Transition: The Former Yugoslav Republic of Macedonia (Copenhagen: European Observatory on Health Care Systems, 2000).

²⁸ For precise information to rehabilitation services in South East Europe, please refer to the report: Pascal Granier, "Physical Rehabilitation services in South East Europe - Disability Monitor Initiative" (Belgrade: Handicap International, 2004).

of major municipalities. They provide ambulatory services for families of children born with developmental difficulties in terms of early diagnosis and prevention, as well as referrals to relevant specialised institutions (Box 7). These services, mostly located within Health Centres at PHC level, are an opportunity for parents of children with disabilities to obtain multidisciplinary support for the development of their child, in a local setting. Long-term follow-up is provided. Nowadays, two of these Developmental Counselling Centres operate in Macedonia (in Skopje and Bitola), and 37 in Serbia (10 of which are located in Belgrade). Such centres do not exist in smaller municipalities and rural areas, thus restricting the alternatives to residential care for children with severe disabilities.

Community-based rehabilitation services integrated within PHC in Bosnia and Herzegovina

Between 1997 and 2004, Bosnia and Herzegovina established 60 Community-Based Rehabilitation (CBR) centres within its public Primary Health Care system (38 in the Federation of Bosnia and Herzegovina and 22 in the Republika Srpska), with support from ICACBR/Queen's University and the World Bank. Inspired by the CBR model, and adapted to the country's health care system, this is a success story of inclusion of

rehabilitative care within primary health care, based on collaboration between various sectors of the community. Such an integrated model of rehabilitation also aims at ensuring better access to medical care for persons with disabilities, through an interdisciplinary approach and appropriate referral (Box 10).

2.3. Looking ahead

Too often, people with disabilities remain excluded from mainstream health care services, and are systematically oriented towards specialised medical institutions. Nevertheless, in some places they can receive comprehensive medical services and (re)habilitation care within the public PHC level. Radical improvements in health care systems are needed to achieve this on a larger scale:

- **Efforts should be made to mainstream disability in Primary Health Care, which implies a sensitisation of all health professionals such as physicians and nurses during their studies (refer to part III chapter 2.3),**
- **There is an urgent need to develop (re)habilitation services within Primary Health Care, in order to improve access to (re)habilitation services, and to achieve an efficient continuum medical care - (re)habilitation.**

BOX 7

Centre for follow-up of children at risk of developmental difficulties in Skopje

This centre is situated within the polyclinic primary health care facility in Skopje in Macedonia and was created 1991. The centre provides the following services to parents of and to children with disabilities or other developmental difficulties:

- Early detection,
- Registration and diagnosis of children with disabilities and other developmental difficulties
- Early interventions and treatment,
- Advice and counselling for parents individually or in groups,
- Multidisciplinary team work with specialists such as paediatricians, defectologists, psychologists and nurse,
- Referral to specialised institutions or hospitals,
- Training to other primary health care units in child development.

Staff

2 paediatricians
2 defectologists
1 psychologist
1 nurse

A support for children with disabilities to live within their families

Such type of structure makes it possible for parents of children with developmental difficulties to find within their communities the medical care, follow-up and counselling they need for their child, without having systematically to refer to a specialised institution.

3. (RE)HABILITATION: FROM SPECIALISED HOSPITAL CARE TO COMPREHENSIVE COMMUNITY-BASED SERVICES

UN Standard Rule 3. Rehabilitation (extracts)

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

- States should develop national rehabilitation programs for all groups of persons with disabilities. Such programs should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality,
- All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.

(Re)habilitation: a pre-condition for full participation

Referring to the UN Standard Rules, (re)habilitation is a pre-condition for equal participation of persons with disabilities. Medical (re)habilitation is only one of several components of rehabilitation, which is a comprehensive process, aimed at enabling persons with disabilities to reach and maintain their optimal level of independence. It therefore includes other types of interventions in various sectors such as education, social services and employment. However rehabilitation is still considered from a rather strict medical point of view in the region's care systems. For that reason, other types of rehabilitation interventions are separately analysed within the next chapters of the report.

Consistent with the principles of choice and participation, (re)habilitation should always be based on the individual needs and expectations of each person. The principle of proximity is at best achieved through a community-based approach: "*Community Based Rehabilitation is a strategy within general community development for rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services*²⁹".

3.1 Legacy and current context

(Re)habilitation reduced to a medical and fragmented approach

Disability continues to be considered as an individual pathology in the countries of South East Europe, to be cured by specialists such as defectologists (Box 8) and physiatrists (physicians specialised in Physical Medicine and Rehabilitation - PMR). Except for persons with mild disabilities, this treatment is provided mainly within specialised rehabilitation institutions.

In contrast to the comprehensive and interdisciplinary ideal model of (re)habilitation described previously, the organisation of rehabilitation care that prevailed in the region's institutionalised care systems was very hierarchical, overspecialised and fragmented, with the physician often having sole responsibility for assessment and planning of treatment regimes. Other PMR professionals each performed their part of the prescription without a comprehensive overview of the person. This organisational structure still characterises most of the system today, and results in stereotyped treatments, which do not usually take into account environmental factors and individual expectations.

Education of rehabilitation professionals

The training of rehabilitation professionals reflects this dominant role of physicians. Even though the technical level of rehabilitation professionals trained in the former Yugoslavia and in Bulgaria was acknowledged as good, it was very much oriented towards physical treatments (such as electrotherapy, thermo-therapies or hydrotherapy) and essentially based on medical diagnosis and functional status, with little attention paid to the social environment and individual expectations. There has been limited evolution on these aspects, partly due to a lack of opportunities for updating professional skills and knowledge.

Besides physical rehabilitation, the profession of psychology is poorly developed. The profession did not exist under the communist regimes of Albania and Romania, and was only introduced there recently. In Albania for instance, a psychology educational program was established in 1996, as a part of the department of pedagogical sciences and psychology. It is a 4-year post-secondary state diploma. Only 30 to 35 students enrol per generation and there are few lectures on disability.

²⁹ ILO, UNESCO, UNICEF, WHO, Joint Position Paper on "CBR for and with People with Disabilities," (ILO, UNESCO, UNICEF, WHO, 1994).

BOX 8**Defectology in South East Europe****What is Defectology?**

Defectology, based on the work of L.S. Vygotsky, a Russian developmental psychologist was created during the 1930's. The profession subsequently developed in most of the eastern communist countries. Defectology defines itself as "a unified approach to the study and treatment of people with disabilities. Within this approach children with disabilities are viewed as bio-psychosocial beings governed by the same laws of development as other children but with complications resulting from an impairment. Defectology is a multi disciplinary approach that brings together psychology, medicine, philosophy, sociology and political theory in order to diagnose, educate and rehabilitate people with mental and physical handicaps³⁰".

Defectology comprises of 5 specialities:

- Oligophrenology deals with persons with intellectual disabilities,
- Somatopedology deals with persons with physical impairment,
- Tiphlogy deals with persons with visual impairment,
- Surdology deals with persons with hearing impairment,
- Logopedy deals with persons with speech impairment.

Defectologists work mainly with children with disabilities, often in special schools or in centres for social work (where they expertise the developmental skills of children with disabilities, monitor their development and provide occasional treatment), but they can also be employed in rehabilitation centres, special hospitals or social residential institutions.

Defectology Institutes (as branches of Faculty of Philosophy) exist in Tuzla (Bosnia and Herzegovina), in Belgrade and in Skopje. Degree courses are 4 years in duration.

Defectology within the de-institutionalisation process

The discipline has been criticised by several authors. According to Jonsson (1998) "Defectology has a strong medical orientation that defines disability as a diseased state (invalid, defective, abnormal children with mental or physical disease) or the problem of the "abnormal" individual. The role of the environment in supporting or burdening the individual is ignored. Treatment consists of a diagnosis, segregation of the "normal" and "abnormal" individuals and correction of the defect³¹".

Despite of this ideological background, in some countries the defectology institutes succeeded in reforming and became valuable stakeholders in the de-institutionalisation process. In Croatia and in Romania they became institutes for training of special educators, while in Macedonia the defectology institute has been more and more involved in inclusive education programmes in partnership with UNICEF and Save the Children over the past decade. The role of defectologists in Macedonia is increasingly that of a resource bank³².

Absence of professional standards in physiotherapy

The physiotherapy profession is poorly recognised in the region, often relegated to this role of executants. The profession does not even officially exist in Albania. In the former Yugoslav republics, the education system for physiotherapists was two-tiered:

- *Medical secondary schools* provided a 4-year education programme for various health technicians, including physiotherapy technicians entitled to provide hydrotherapy, massage, electrotherapy, and basic

physical therapy treatment,

- Technicians could continue their education for 2 or 2.5 more years at the *Physiotherapy College* (high school), and become high-level physiotherapists.

In practice, the hierarchy between the two levels was and is not always respected. For instance, in rural areas, or in provinces or republics which did not have a Physiotherapy College (like the UN administered province of Kosovo or Macedonia), most of the staff working as physiotherapists are actually physiotherapy technicians, without the competencies required for the job.

³⁰ Ajdinski, L. Florian, "Special education in Macedonia," European Journal of Special Needs Education Vol. 12, 2 (Macedonia, 1997): 112-126.

³¹ Ture Jonsson, "Strengthening the Special Education System in Armenia," (Stockholm: Swedish International Development Agency, 1998) Cited in: David Tobis, "Moving from Residential Institutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union," (World Bank, 2000): 9.

³² "The Process of De-institutionalization in Macedonia" UNICEF 2000; and "Integration process in R. Macedonia," Report from the seminar of Union of Defectologists of R. of Macedonia, experiences from the integration, inclusion and de-institutionalization of children with disability and the role of the defectologist in regular schools (December 2002).

The absence of the occupational therapy profession in most countries

"Occupational therapy is a profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation. Examples include teaching new techniques and providing equipment which facilitate independence in personal care and reducing environmental barriers³³"

The profession of occupational therapy, which places the emphasis on participation and environment by using a holistic approach, is almost absent from the region. The exception is Serbia which is the only country with a high school for occupational therapists. However, even in that country, out of 550 qualified occupational therapists, only about 150 are employed as such, and their field of work is often restricted to psychiatry³⁴. In Bosnia and Herzegovina some occupational therapy programs were implemented in the framework of Community Based Rehabilitation programs, but the profession is not officially recognised. Of the neighbouring countries, Slovenia is the only country where occupational therapy is well established and recognised. In Croatia an occupational therapy high school program was established in 1986, of 186 graduates, only 45 actually work as occupational therapists³⁵. In Romania, Bulgaria and Hungary occupational therapy does not exist yet.

A network of specialised rehabilitation facilities

As described in the previous chapter, rehabilitation services are rarely available at primary health care centres. They are generally provided through a network of highly specialised rehabilitation facilities, including specialised rehabilitation hospitals and climatic centres or spas (Box 9). Each rehabilitation centre is designed for a certain type of disability. In the former Yugoslavia some of those centres were well equipped, with professionals trained abroad in modern rehabilitation methods, and the quality of services was acknowledged as good. The cerebral palsy department and occupational therapy unit in Belgrade that opened in the 1950s for example, still has complete teams of well-trained professionals. However, this overemphasis on diagnosis means that the provision of rehabilitation services is centralised in one or just a few facilities, so that people often have to travel far from their communities and families in order to access services.

The breakdown of the former Yugoslavia exposed the new countries and regions to a range of varied situations. Serbia and Montenegro and to a certain extent Slovenia, inherited most of the best equipped rehabilitation facilities and training resources, while Macedonia and the UN administered province of Kosovo in particular are far less well equipped. The fragmentation of government institutions in Bosnia and Herzegovina led to a dramatic restriction of access to rehabilitation services in some Cantons and municipalities. The lack of resources within the healthcare system over the past decade has worsened the existing regional discrepancies between best-

BOX 9

The unclear position of Spas (Banjas) within the rehabilitation care system

Throughout South East Europe, there is a long tradition and history of hydrotherapy within many resorts that have been in use for centuries. In the former Yugoslavia, many of them were established as **climatic centres or spas (banjas)**, providing water therapy or climatic rehabilitation, and primarily intended for rehabilitation of workers (treatment of work-related injuries and prevention of disabilities). Over time some of them developed specialized services and offered medical rehabilitation as well. Thus the distinction between specialized rehabilitation hospitals and spas (banjas) is not so obvious nowadays:

- Some spas (banjas) turned into recreational centres offering some kinds of physical therapies. They are not part of the health care system, have private or semi-private status, and provide services for self-paying clients only,
- Others became rehabilitation centres, considered to be specialised rehabilitation hospitals. In addition to public funded beds, many opened additional beds that are offered, either to self-paying patients or for "health tourism". Those centres provide medical rehabilitation and recreational / climatic rehabilitation at the same time. Very often, there is neither clear distinction of services nor separate allocation of human and material resources between those two types of services within a given structure.

This confusion of services, with unclear financing mechanisms and absence of standards for physical rehabilitation services provided by these facilities, contributes to the creation of discrepancies in the quality of services provided and in the patients' access to rehabilitation services.

³³ Definition from the World Federation of Occupational Therapists, available at: www.wfot.org.au

³⁴ Interview with the Secretary of the Serbian Association of Occupational Therapy, Belgrade, May 12th 2004.

³⁵ Information from the European Network of Occupational Therapy in Higher Education, available at: http://www.enothe.hva.nl/edu/facts_and_figures.htm

BOX 10**International Centre for the Advancement of Community Based Rehabilitation (ICACBR), Example of community-based rehabilitation system in Bosnia and Herzegovina partners in the development of rehabilitation services at the community level****Queen's University, Kingston, Canada (by Djenana Jalovic)****Project background**

Since 1993, the ICACBR, Queen's University has been playing a major role in the reorientation and restructuring of rehabilitation system in Bosnia and Herzegovina. With the support from the Government of Canada through the Canadian International Development Agency, and together with the partners from the Federation of Bosnia and Herzegovina and Republic of Srpska as well as its international partners, the ICACBR has taken part in the establishment of the over 60 community based rehabilitation (CBR) clinics throughout the country. The major focus of the ICACBR's work has been on creating accessible environment, policies and support systems at the community level for disabled people to be able to live independently and fully participate in the social and economic life of their communities. Activities included continuing education of CBR centres personnel to upgrade their clinical skills, development of policies which support provision of CBR at the primary health care level, policy and management training for a variety of stakeholders working in disability and rehabilitation sectors and introduction of peer support concept. The introduction of peer support activities implemented by people with disability themselves significantly contributed to raising disability awareness as well as profiling people with disabilities as productive members of society.

Project objectives

The design and implementation of ICACBR's project in Bosnia and Herzegovina was based on extensive experience and has resulted in enhanced understanding of the region and its priorities. Efforts are made to ensure that there is a continuing transfer of knowledge between partners. Increased knowledge about disability and approaches to addressing the needs of people with disabilities in the community facilitates the development of policies that promote inclusion and equal rights of people with disabilities. Participation of persons with disabilities and other stakeholders including health and social sector professionals, policy makers, educators, etc. in all stages of rehabilitation system and policy development is crucial to the successful implementation of CBR programmes. Increased knowledge, inclusive policies and participation of multi-stakeholders, ensure improved access for people with disabilities to rehabilitation, disability and support services at the community level.

Project methodology

Partnership and an integrated approach to CBR service and policy development are a major contribution to the sustainable development of a rehabilitation system in Bosnia and Herzegovina. Coordination in this multi-partner program has resulted in integration of CBR centre reconstruction, education on clinical practice, peer support, management and policy development. The team approach to project development and implementation has been identified as central to facilitating the empowerment of all stakeholders at the treatment, CBR centre administration and policy level. Multidisciplinary team approach to education involving persons with disabilities and therapists in the educational program was an effective mechanism for demonstrating competence and importance of including persons with disabilities and therapists in

clinical, education, and policy and program decision-making.



Queens University CBR educator with child, spring 2004

BOX 11**HandiKos - DPO and service provider in the UN administered province of Kosovo**

HandiKos (Association of Paraplegics and Child Paralysis of Kosovo) is an association of people with disabilities established in 1983. Its mission is to support the full inclusion and participation in society of people with disabilities. The organisation has three main objectives:

- **Political development and self-representation** - lobbying and advocacy for policy changes, monitoring of implementation of policies, awareness and campaign for inclusion and participation,
- **Service provision for people with disabilities** - lobbying and promotion of community-based services and management of 10 community centres, organisation of sport and leisure activities, distribution of orthopaedic appliances,
- **Financial independence for people with disabilities** - lobbying and advocating for proper legislation for employment of people with disabilities, organisation of public round table discussions.

equipped facilities and regional rehabilitation centres. In Albania the situation is even worse, with a dramatic lack of facilities and rehabilitation professionals³⁶.

3.2 Initiatives for change

As a response to this specialised system and to the lack of rehabilitation services at community level, several pilot exercises in establishing different types of community-based services have been initiated, and the following gives some highlights of successful experiences in various countries throughout the region.

CBR in Bosnia and Herzegovina

Since 1997, a system of CBR centres has been initiated in Bosnia and Herzegovina, initially in the Federation of Bosnia and Herzegovina (FBiH). Since 2003 it also covers the Republika Srpska. The Ministry of Health, in partnership with the World Bank, the Canadian International Development Agency (CIDA) and ICACBR/Queen's University established 38 CBR centres within the Primary Health Care centres that provide multi-disciplinary rehabilitation. In Republika Srpska, 22 CBR centres were established with support from CIDA, the Japanese Government and ICACBR/Queen's University. They now function in a similar fashion to those in the FBiH. The team profile in the centres consists of a physiatrist, physiotherapist, physiotherapy technicians and nurses. Box 10 provides a description of the project development, provided by courtesy of ICACBR /Queen's University.

Community-based rehabilitation initiatives in the UN administered province of Kosovo

HandiKos - an organisation of people with disabilities in the UN administered province of Kosovo (Box 11). HandiKos has established a network of 10 community centres in major municipalities where children with disabilities can benefit from Primary Therapy Rehabilitation and psychosocial activities provided by so called 'community social workers'. This development of a community based rehabilitation system was made possible mainly due to the strong financial and technical support of international humanitarian organisations.

It was initially developed without formal links to the health and social welfare system. This was due in part to the difficulties encountered in the post-emergency period and the lack of proper institutions to govern the new initiatives. It was developed to fill the gap left by medical and social rehabilitation services, which were still not developed or accessible within ordinary services system.

This large outpouring of support during the emergency phase has resulted in HandiKos now struggling to sustain these centres financially and technically. This is due to the drastically decreased support from the international community and the lack of involvement of public stakeholders. During the last year though, a strategy of lobbying for including CBR services within the general health and/or social welfare system has been initiated in a dialogue between HandiKos and the relevant ministries. All these difficulties also have to be viewed within the overall situation in the UN administered province of Kosovo, which still does not have a defined legal status or proper legal system, as well as poor enforcement mechanisms. Few services and organisations are able to sustain their activities in such conditions.

Day Care rehabilitation centres - filling the gap of (re)habilitation services at community level

Due to the lack of access to de-centralised (re)habilitation and educational services, a parallel system of so called "Day Care centres" has been developed during the last 10 years, often with the support of international humanitarian organisations wishing to promote a de-institutionalised and community-based service system. These Day Care centres were initially designed for children or young adults and were thought to be an alternative to, and even replacement for social or medical residential institutions. The main innovation with these types of centres was that they brought about the concept of inter-disciplinary teamwork as well as a social approach to disability, combining education with varying types of rehabilitation and social services. The various Day Care centres actually adapted themselves to suit the needs identified within the community where they were established.

³⁶ Pascal Granier, *ibid.*

BOX 12

Karin Dom Foundation - Day Care centre providing rehabilitation services in Bulgaria

Background to the development of Karin Dom Foundation

The creation of the Karin Dom Foundation was based on the issue of combating the old system of residential institutions that existed (and still exists) in Bulgaria for children with disabilities. This NGO was registered in 1994, and from the outset, a strong partnership was developed with international experts, mainly from the UK. The process of development of the centre is presented below:

- Initial research into the type of activities and centres in the UK followed by various study visits throughout Bulgaria,
- Establishing relationships with international experts such as physiotherapists and psychologists,
- Exploratory mission to evaluate the site of the Day Care Centre (Varna municipality) and identification of professionals to be employed,
- Core team of professionals chosen and trained according to the approach of experts from the UK (teamwork, social approach, interdisciplinary assessment and individual action plans),
- Definition of the mission, objectives and direction of the Day Care centre was set by the Core team,
- Contacts made with families of children with disabilities in the surrounding area, and an awareness and sensitisation campaign was sponsored for these families,
- Activities commenced initially involving 5-6 families,
- Creation of a Parent Support group that later on received training in lobbying and finally registered as a Parent Association of children with disabilities.

Slowly the centre became more and more recognised within the Varna community providing daily care for children with physical, mental and autistic disabilities, and today the centre is functioning as a 'Therapy and Consultation centre' and can show following results:

- 28 staff employed in the centre,
- Services provided are physiotherapy, speech therapy, individual treatment, educational activities, support for inclusion into mainstream education, counselling for families, sensorial treatment etc,
- 140-160 children attend the centre per year and 35-40 children on weekly basis,
- 27 children have been integrated in mainstream education since 1997,
- Each child has its own action plan that is continuously evaluated and adapted.

Development of the training and resource department

In 2001, the Karin Dom Foundation decided to implement a project to "Develop Karin Dom as a Training and Resource centre for professionals". This was done in order to address the need for training and support to other Day Care centres, or professionals within children's homes (orphanages or social institutions). First, a consultation process with the families of the children in the centre was carried out, in order to have their full support for the implementation of this change as it was envisaged that the centre could only operate in the mornings. Once agreement was reached training programmes tailored to the specific needs of each institution were designed and implemented. Training was conducted either in-situ or within the premises of Karin Dom. Some achievements were:

- 312 participants from 22 towns and villages throughout the country,
- 123 students from universities in Varna and surrounding cities,
- 5000 leaflets were printed and distributed to parents regarding 10 different types of disabilities,
- Unemployed persons trained as personal assistants to children with disabilities integrated in mainstream education.



Montessori group activities in Karin dom centre



One example of these Day Care centres is the Karin Dom Foundation. This NGO, based in Varna, Bulgaria, has been working in the field of rehabilitation for children with disabilities for 10 years (Box 12). They provide comprehensive multi disciplinary rehabilitation services, and have continuously developed their activities and human resources towards the trends of de-institutionalisation. The main strength of Karin Dom as an organisation has been their readiness to adapt to the changing environment, both in regards to the needs of the Varna community, and according to the overall development in Bulgaria in terms of legislation and de-institutionalisation. They also adapt to the changing opportunities for the financial sustainability of their activities.

3.3 Looking ahead

This assessment indicates that there is both a lack of physical and medical (re)habilitation (PMR) services at the community level and a low quality of care within existing services. The main weaknesses of the system are:

- (Re)habilitation services are still centralised and accessible only after prescription of specialised doctor or medical commission,
- Certain medical professions such as occupational therapy, psychology and special education are still lacking,

- Private (re)habilitation service providers or NGOs/ DPOs cannot be subcontracted for the services they deliver and therefore lack options for sustainability,
- Lack of high-level professionals and management capacities.

There are however, some strong elements of change, where increased awareness of the social approach and multi-disciplinary teamwork has been initiated in several services. New community-based services such as Day Care centres have been shown to provide quality services according to new models giving users a more active role in defining the treatment plan.

The following improvements and developments are recommended in order to improve the access and quality of services for people with disabilities:

- **There is an urgent need to develop PMR services within Primary Health Care, in order to improve access to (re)habilitation services (as mentioned in 2.3),**
- **A strong need to establish professional standards and quality standards for health professionals,**
- **Need for better coordination, interdisciplinary approach and networking,**
- **Improve the involvement of users and their representatives in the development and evaluation of community-based (re)habilitation services.**

SPOTLIGHT 1

MOTIVATION ROMANIA FOUNDATION IN BUCHAREST

Motivation Romania Foundation grew out of a project initiated in 1993 by the International Federation of Red Cross and Red Crescent Societies and Motivation Charitable Trust, a British Registered Charity, to establish a wheelchair production workshop in Romania. Motivation Romania registered as an NGO in 1995. To the present day, over 1,600 wheelchairs-active and, more recently, sports style and special seating for children with cerebral palsy-have been produced and donated to persons with disabilities from Romania, Bulgaria and Moldova. In 1995 the first project of Active Rehabilitation was initiated and 5 wheelchair users attended an Active Rehabilitation (AR) camp in Poland, and at the end of 1995 the first AR program was launched in Romania.

Main activities of Motivation

- Production of wheel chairs and adapted seating units for children with cerebral paralysis (where the producers are persons with disabilities themselves),
- Managing Active Rehabilitation programs for wheel chair users in their centres and during summer camps in accessible facilities,
- Community Centre that provides access to conference facilities sport events, urodynamic treatment and peer counselling,
- Independent Living houses which offer models for wheel chair users,
- A Day Care centre and three Family Group homes have been established for 22 children de-institutionalised from Ilfov county,
- Seminars, trainings and peer counselling in Romania, but also in Moldova, Bulgaria, Albania and Estonia.

Development of the concept of Active Rehabilitation

After the initial pilot project of AR, Motivation organised several summer camps of Active Rehabilitation in Romania, and in 1997 they decided to make a pilot project of establishing a Centre for Active Rehabilitation and Social Integration. The idea was that persons who after accident needed a wheel chair would have a comprehensive rehabilitation, clearly focused on independency and autonomy, but wider than just during a summer camp. This was a success and the program is still running today, the only problem being the financing of the activities. The team of Motivation has also supported the set up of a summer camp in Albania together with ADRF.

Services offered in the Active Rehabilitation program

Motivation provides a comprehensive set of services including evaluation, the prescription and adaptation for the wheelchairs and then training the person in order to achieve maximum independence. The clients have the possibilities to stay either during a 10 days session in the centre, a 6 days summer camp and they can also attend a one day seminar.

Content of the Active Rehabilitation program:

- Medical assessments (looking in particular at specific problems of wheelchair users - e.g. pressure sores, urinary tract)
- Providing advice and work to make the home accessible,
- Wheelchair maintenance skills,
- Independent living skills,
- Computer training courses and other professional training (depending on funding).
- Psychological counselling and professional orientation counselling,
- Peer group discussion,
- Wheelchair sports (tennis, basketball).

Capacity of the different components of Active Rehabilitation:

- 14 wheelchair users at the Motivation Community Centre,
- 5 wheelchair users in the independent living module,
- 12 wheelchair users and 12 personal aides at the Motivation accessible summer camps.

Professional staff in the Active Rehabilitation program

The team that implements the Active Rehabilitation programs at Motivation Romania Foundation is made up of:

- 2 physiotherapists,
- 4 active rehabilitation trainers (wheelchair users),
- 3 sports instructors / trainers,
- 1 social worker,
- 1 psychologist,
- 1 physician,
- 1 nurse.

Summary

Motivation is, like most NGOs in the region, mainly financed through projects. In 2004 though, they finally received a certification from the National Health Insurance Agency (NHIA) for their wheelchair production, and when a person receives a wheelchair based on the approval of the NHIA, Motivation is reimbursed for the cost of the production. The only limitation is that this reimbursement amount is based on an average cost of production and is the same for all producers regardless of their actual production costs. The other services are so far free of charge and the estimated costs per day for one client in the Active Rehabilitation program is around \$12/day. Throughout the years they have become well-known in their field in Romania, and they have as well develop several initiatives in the field of sports for persons with disability and have a close connection with the committee of Special Olympics in Romania.

Their program of Active Rehabilitation shows an excellent example of both an interdisciplinary teamwork between medical staff and staff from the social and educational field, as well as the necessity of peer counselling in order to work on the self-autonomy. Most of the employees within Motivation are themselves wheelchair users, and as such is showing the possibilities for the clients. Several of the users of Motivation's programs have improved their skills of independency but more of all they have raised their self-esteem and as such have the most important skills for self-empowerment.

4. SUPPORT SERVICES: TOWARDS INCREASED LEVEL OF INDEPENDENCE FOR PEOPLE WITH DISABILITIES BY PROVIDING BETTER ACCESS

UN Standard Rule 4. Support services (extracts)

States should ensure the development and supply of support services, including assistive devices and equipment for persons with disabilities, personal assistance and interpreter services, to assist them to increase their level of independence in their daily living and to exercise their rights.

- States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility.

The lack of access to support services such as assistive devices, personal assistance or interpreter services may deprive persons in need of the opportunity to live a self-determined life integrated into society. The issue of access to supportive services for persons with disabilities is crucial in South East Europe, either because they hardly exist (in the case of personal assistance) or for financial reasons (in the case of technical aids or ortho-prosthetic devices).

4.1 Legacy and current context

The absence of Personal Assistance services

In the logic of an institutionalised care system, the two main options for a person with a more severe level of disability are either to live within the family, or in a social residential institution. Living independently within the community is rarely an option; therefore services to support such an independent life were not developed within the region's care systems. For those who stay within their families, in the context of strong familial solidarity that still characterises most of the societies in the region, it is often a family member who fills a role of assisting the person. This is emphasised even more due to the current social welfare support system providing *third person cash allowances for the assistance of another person in the activities of daily living and the financial compensation for a mother staying at home to take care of a child with disability*. Most of the time this support finances a family member, and is generally combined into the family's overall income. **Personal Assistance** services remain almost non-existent.

Irregular quality of ortho-prosthetic devices and technical aids

The situation differed significantly for persons with an isolated physical disability. Applying the medical approach, they were considered "curable" or potentially able to be reintegrated into the workforce. Production of technical aids, equipment and ortho-prosthetic devices was therefore developed in all countries, and

those services were generally provided free within the public health care system.

Ortho-prosthetic (OP) workshops existed in all countries in the region, mostly as large state companies such as the **Rudo** workshops in the former Yugoslavia or **Romhandicap** in Romania. Recently, these workshops have been privatised or have become semi-public. Many private workshops have also been created. Ortho-prosthetic devices continue to be financed directly or indirectly through the state budget, however. The largest workshops also produce wheelchairs and walking aids, as in the case of Rudo in Belgrade, Slavej in Skopje and Romhandicap in Bucharest, which also produces other assistive devices such as adapted controls for cars and various technical aids.

Despite the significant improvements in the ortho-prosthetic sector in the context of war victims and landmine victims' rehabilitation programs³⁷, large discrepancies are observed in the quality of existing services from one facility to another³⁸. This is primarily linked to the lack of recognition of the profession in most countries in the region, and to the absence of formal education programs in this field. In several countries, the selection of service providers is now made through open tender procedures (in Serbia and Montenegro and in Macedonia for instance), but this is not accompanied by adequate quality control procedures.

Problems of financial accessibility

The most worrying point regarding ortho-prosthetic services and technical aids in the region certainly is the disparate access to these devices, due to their high cost (the technological requirements in the region are very close to the Western Europe's) and to decreased public subsidies for ortho-prosthetic devices. Co-payments have been set up in most countries, but the financial burden can become prohibitive, especially for mid or low-income households. In Bosnia and Herzegovina for instance, this co-payment can range from 10 to 50%, which according to the type of device can range from € 100 to more than € 1,000³⁹. In the UN administered

³⁷ Sheree Bailey, "Landmine Victim Assistance in South East Europe," (Belgium: Handicap International: September 2003).

³⁸ Pascal Granier, *ibid*.

³⁹ Handicap International and UNICEF, "Landmine Victim Assistance in Bosnia and Herzegovina - working paper to support the elaboration of a long-term strategy," (Bosnia and Herzegovina: Handicap International and UNICEF, 2004).

province Kosovo, due to the absence of health care financing system patients have to pay the full price for their wheelchairs and other equipment, while ortho-prosthetic devices are still provided free of charge thanks to foreign financial support. The international aid that initially provided some assistive devices in the UN administered province of Kosovo is decreasing, whilst the national public budgets for social security do not seem to be ready to take over.

4.2 Initiatives for change

Development of Personal Assistance service in Serbia - managed by users

An interesting initiative to develop the Personal Assistance support service (Box 13) is implemented by **Centre for Independent Living of Serbia** (CIL Serbia) in Belgrade. CIL Serbia is a cross-disability organisation established in 1996, which promotes the philosophy of Independent Living and its implementation in Serbia. Their **Personal Assistance project** is fully described at the end of this chapter presented in Spotlight 2. The unique nature of this programme is that the service is under the full control of the person with disabilities. This implies of course, that the person with disabilities possesses the potential to achieve a certain level of independence and self-confidence. Therefore, one of the objectives of this programme is to build self-confidence and empower users of the Personal Assistance service. The main message of CIL Serbia is that a person with disabilities must choose and decide on the direction of his/her life.

Pilot project of interpreting service in Novi Pazar - Union of deaf and hard of hearing persons

Interpreting services are another important support service for people with hearing impairments helping to ensure their participation, and as well equal access to information and rights. This service is poorly developed throughout the region, and that is why a small pilot project trying to address this issue in Novi Pazar in south of Serbia is presented here. The Association of deaf and "people hard-of-hearing" implemented a pilot project called "school of sign language" to train public service employees. Professionals from the police, local post office, Centre for Social work, municipal assembly, private companies, developmental counselling centre, students and families of children with hearing impairments, were trained in sign language in order

to support persons with disabilities when needing this type of service. This project was well appreciated in the community, and employed good methodology and will now be implemented in a similar fashion in three other municipalities in south Serbia (Tutin, Raska, and Sjenica). This example shows the value of input (and specific knowledge of the actual situation) by DPOs in the sensitisation as well as training of professionals to bring about sustainable improvements in the daily life of people with disabilities in a cost-effective manner.

Adapted transport service for people with disabilities

In 2002-2003, an adapted transport project in two municipalities in the Republic of Serbia was supported by Handicap International, taking into account lessons learned from previous failures in establishing such service. Nis and Subotica were chosen since there was a clear will on the part of local government to support the project in partnership with DPOs in their community. A DPO working group had agreed on criteria for use of the van prior to commencement of the project and is still coordinating this service with the municipalities.

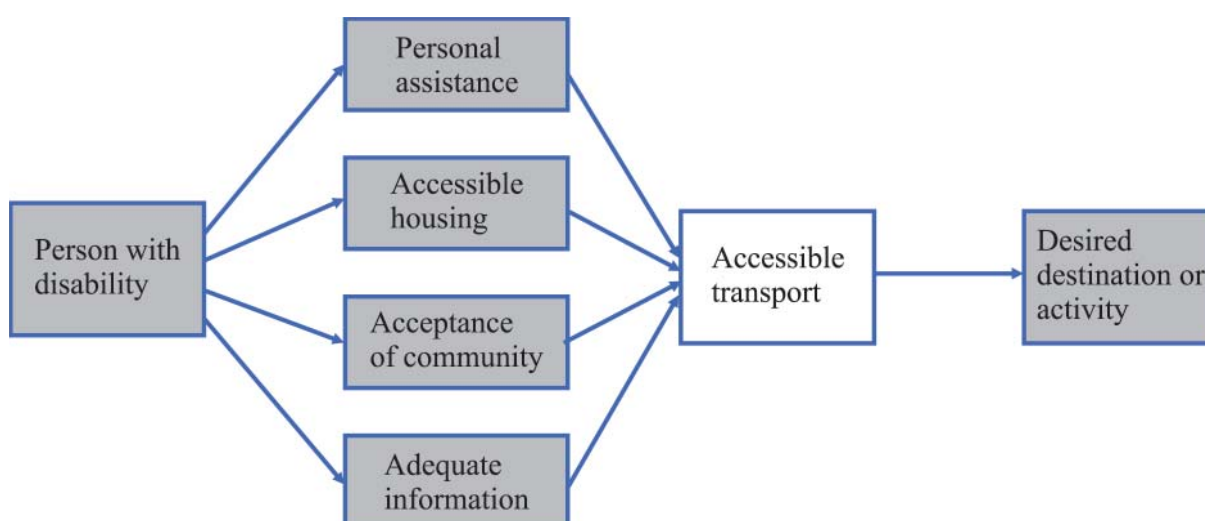
This service is still functioning today with the same partners and is a good example of collaboration between the public sector and civil society. During this project it became obvious however, that access to adapted transportation does not solve the difficulties of getting around in the community. Many people with disabilities cannot manage their mobility independently, and the lack of a personal assistant or support from a family member is a major obstacle to independent movement in the community. Another reason for not being able to use transportation systems effectively is that apartments and buildings are themselves not accessible so that people cannot get in or out of their own homes. Thus it is clear that the issue of special transportation cannot be addressed in isolation, but needs to be the subject of broad and comprehensive planning coordinated jointly between social welfare bodies, local authorities responsible for public transport, ministries of urban and rural planning, as well as organisations of people with disabilities.

Another example where direct lobbying by DPOs has had remarkable results is the campaign for accessible public transport in Tuzla, Bosnia and Herzegovina, which was directed by **IC Lotos**. Their awareness-raising campaigns and negotiations with local authorities resulted in the purchase of a number

BOX 13

Concept of Personal Assistance service

The existence of a personal assistance service (PAS) is one of the preconditions for achieving independent living. A personal assistant who is chosen and employed by the user, provides services to a single user who defines his/her own needs as well as the time and place where assistance will be provided. Users also train their personal assistants in how to best assist them. The term 'Personal Assistance' implies that person who provides services to the user does so in a way that best suits the user and not in a generic manner learned through systematic training. Personal assistance can be provided for basic daily needs or for professional or social activities.

Scheme 4. Preconditions for a person with disabilities to benefit from an accessible transportation system

of new buses adapted for people in wheelchairs or with decreased mobility. The strong point in their advocacy was that accessible buses in general make life easier for the whole population (older persons, parents with trolleys etc). Still, the same difficulties appeared, in fact the staff of IC Lotos reported that no significant increase in the number of wheelchair users actually using buses⁴⁰. This confirms the necessity of the comprehensive approach as illustrated in the scheme presented above.

Towards the professional upgrading of ortho-prosthetic technicians

Developing a high-level ortho-prosthetic technician profession is a pre-requisite for improvement in the quality of various types of ortho-prosthetic devices. As such, the recent establishment of a high-school level education program for ortho-prosthetic technicians in Bucharest can be presented as a best practice (Box 14).

In Bosnia and Herzegovina, the **Centre for International Rehabilitation (CIR)** an American NGO, has established an education program to upgrade skills of ortho-prosthetic technicians. The curriculum, based on international standards, is designed in a modular way, and the theoretical component is completed by distance learning, through the CIR website⁴¹. The practical component and examinations are held in Tuzla. The program is about to be extended to some other Balkan countries. This interesting initiative is limited by the absence of recognition of the profession in BiH, as in most of the neighbouring countries.

4.3. Looking ahead

Switching from an excluding approach to providing services to one that gives an opportunity for the person with disability to choose is possible. This is what the example of the personal assistance services, based on an Independent Living philosophy, developed in Serbia demonstrates. However, access to various types of support services remains limited. In order to promote these support services, at community level, following are recommended:

- **Organisations of people with disabilities should play an important role in collaboration with municipalities and local authorities as well as service providers in the planning of new services,**
- **Organisation of people with disabilities should also have a role in providing training to civil servants in various aspects and sensitisation on accessibility and the needs of persons with disabilities, for example,**
- **Equal financial accessibility to assistive devices for persons who need them should be ensured, notably through the establishment of equitable and realistic cost-recovery systems. This issue must be tackled within a broader framework of defining realistic basic health care packages, transparently and with the participation of organisations of persons with disabilities,**
- **Regional and international cooperation is needed to develop formal professional education in the fields of ortho-prosthetics in order to improve the quality of services⁴²,**

⁴⁰ Information from discussions with the staff at IC Lotos, Tuzla, Bosnia and Herzegovina, June 2003.

⁴¹ Available at: www.cirnetwork.org

⁴² According to WHO and International Society for Prosthetics and Orthotics (ISPO) norms, between 0.5 and 0.8% of a total population would need ortho-prosthetic devices; and a ratio of 1/500 to 1/1,000 professional per number of persons needing ortho-prosthetic devices is required. Given the small size of most countries in the region, only a small number of professionals are required per country; therefore the establishment of training facilities within each country might not be needed.

- **There is a need of redirecting resources from institutional care towards the development of these support services.**

BOX 14

The education programme for high-level ortho-prosthetic technicians in Bucharest

In October 2003 Romania initiated a three-year education program for ortho-prosthetic technicians. The program is set at post-secondary level, and the Romanian Ministry of Education and Research validated the curriculum, which is based on Western European standards in July 2003. The Ministry also established the profession of high-level ortho-prosthetic technician on the official list of professions. Until then, the technicians working in ortho-prosthetic workshops were 'confectioners', meaning low level technicians without formal education from various backgrounds (handcrafters, mechanics, engineers...), and there were no professional standards. Formerly most of them were trained internally via a 9-month apprenticeship in the public ortho-prosthetic company Romhandicap.

19 students are enrolled in the first promotion. The Romanian teachers receive technical support from Handicap International and the ortho-prosthetic high school of Valence in France.

Romania is the first country in the region (except Slovenia) to have established a formal training for high-level ortho-prosthetic technicians, and thus to have set official professional standards. This should allow a significant improvement of the quality in this domain.

Note: The 4-year Slovenian ortho-prosthetic education program (including a one year internship) is affiliated with the University College for Health Studies in Ljubljana. Most of the lectures take place in the ortho-prosthetic department of the Institute for Rehabilitation.

SPOTLIGHT 2

CENTRE FOR INDEPENDENT LIVING IN SERBIA

Centre for Independent Living of People with Disabilities of Serbia (CIL Serbia) was founded in Belgrade in 1996 and it works on the promotion of human rights and the potential of persons with disabilities. The mission of CIL Serbia is to promote the philosophy of Independent Living and create conditions for its implementation in Serbia⁴³. It is based on the cross-disability principle, i.e. its members are persons with various types of disabilities who are bound together by common needs and interests. CIL Serbia's activities take place both through network of its local branches in 6 cities in Serbia and through central office in Belgrade. Its main activities include:

- Expanding the network of centres for Independent Living at the grass-roots level,
- Promoting human rights as well as the UN Standard Rules for Equalization of Opportunities for Persons with Disabilities,
- Organising education and capacity-building for persons with disabilities and general awareness raising about the status and rights of persons with disabilities,
- Working towards the creation of Personal Assistance Services for people with disabilities,
- Working towards the creation of an accessible environment,
- Campaigning and awareness-raising on the specific needs and the status of women with disabilities
- Research and publishing pertaining to various disability issues,
- Advocacy work including monitoring and lobbying for changes of existing legislation and adoption of new legal acts that would improve the status of persons with disabilities.

Since its establishment, CIL Serbia has completed many projects and activities aimed at raising awareness around the Independent Living philosophy and initiating activities towards its achievement in Serbia. All of CIL Serbia's projects have been development oriented, working on information provision, skills development and the strengthening of people with disabilities as well as the improvement of their quality of life. Over the past 3 years, CIL Serbia developed a pool of its own trainers who are persons with disabilities and conducted educational and disability awareness raising workshops and seminars in more than 30 cities throughout Serbia, whose participants were both people with and without disabilities.

The work of CIL Serbia has a strong advocacy component. The Centre has its own group of disability experts in legislation, whose main tasks are to follow the legislative process in the country, evaluate government policy regarding disability and monitor implementation and propose measures to improve legislation. One of such examples is the lobbying initiative that brought for the first time in Yugoslav history, a change in article 3 of the Charter on Human and Minority Rights, which is part of Serbia and Montenegro's Constitutional Acts, where it is stated that it is forbidden to discriminate people on the grounds of disability. Currently CIL Serbia's legal expert is actively taking part in the work on the UN Convention on the Protection of Rights and Dignity of People with Disabilities, as an official member of Serbia and Montenegro's delegation to the UN.

Pilot project of Centre for Independent Living Serbia

With the financial support of OXFAM, the Centre for Independent Living in Serbia organised an experimental project of Personal Assistance Service (PAS) in 2000-2001 in Belgrade, as an alternative form of support to people with disabilities. The aims of this project were to estimate the demand for this type of support, identify changes that occurred in the lives of users, analyse and compare the quality of services provided through the Personal Assistance Service and to gauge institutional support. The project included a research study that was published at the end of the pilot phase.

Second phase of the PAS project

On the basis of the first experience and research results, CIL Serbia, with the help of the Irish and Serbian governments, has initiated a new Personal Assistance Service project. The two-year project started in February 2003 and is being implemented in four cities: Belgrade, Smederevo, Leskovac and Jagodina. There are 40 beneficiaries with 43 personal assistants allocated.

Aims and Objectives

The project has many objectives, such as the establishment of the first consumer controlled Personal Assistance Service in Serbia, which is regarded as a key aspect of independent living of people with disabilities. How was this achieved? Initially, a series of training sessions and workshops were held for both users and personal assistants. User workshops were held on several topics, including the philosophy of Independent Living, the assessment of the user's own needs and key criteria for the selection of assistants. The National Employment Office was involved in the project by helping in advertising as well

⁴³ Rajkov, Gordana: "Independent Living and Yugoslav Experience" 2003. Internet publication URL: <http://www.independentliving.org/docs6/rajkov200303.html>

as security testing for potential personal assistants, who were then interviewed and chosen by the users themselves. The workshops organised for assistants included training on key approaches to disability and training on lifting, feeding and toiletry of people with disabilities. Various training methodologies were used including: presentations by facilitators, work in small groups, debates, exchange of information and experiences, practical exercises, case studies and role-playing. The project manager insists that all workshops are based on the participatory principle.

Concurrently with the workshops, lobbying and advocacy activities are taking place. The philosophy of Independent Living and the Personal Assistance Service project are promoted through meetings and round tables with the presence of the media and politicians. An integral part of the project is the Participatory Action Research that is aimed both to measure the changes in quality of life of users and cost-effectiveness of the service and develop recommendation on how to mainstream this type of social support for disabled people.

The Personal Assistance Service became operational in August 2003 and even after the first period of activity significant improvements in the quality of life of users has been noted. Users of the service are starting to identify their real needs and to satisfy those desires that they could not satisfy before:

"Over the last two years my life was reduced to waking up in the morning and then enduring a long hard wait for darkness to come so I could go to bed again. Now, since obtaining an assistant, my life has started to make sense again". User from Belgrade

With the establishment of this project, one step has been taken: people with disabilities are becoming aware of their capacities and potentials. Even this takes time, to quote Ms. Rajkov: "The basic lesson learned is that the process of introducing new concepts and ways of working takes time. Prolonged efforts will have to be made in order to implement new ideas and in particular to introduce new concepts into people's consciousness and to adopt new behaviours and attitudes towards people with disabilities". Moreover, lobbying activities by CIL Serbia are slowly but perceptibly raising the awareness of politicians and the general community. In spite of that, CIL Serbia is currently experiencing great difficulties in providing sustainability of the Personal Assistance Service, as the Serbian Government funds that were supposed to contribute to the provision of service in part of tax and insurance payments for the assistants are still not provided.



Photo taken by CIL Serbia during their project



PAS logo

Life story 2: Becoming independent, from Macedonia

Goran from Macedonia

I was fifteen years old when I was involved in an accident. As a result of poor intervention and treatment by doctors in Skopje I suffered infections and lost two arms and one leg.

No hospital or clinic in Macedonia was able to produce appropriate prostheses. My parents decided to travel all over Europe with my picture to find the right specialists. The Heidelberg orthopaedic centre in Germany had a good reputation. They agreed to provide the treatments I needed. In Germany, I learned how to accept my difference and to live with it in a very positive way. I also learned how to be independent. I found a job and a flat in Germany and lived a very normal life there.

After 10 years, I went back to Yugoslavia. I tried to find a new job. There were many promises, many lies, with no results at the end. I looked for a job as a translator. But everyone I met thought that a person with disability could not do this job, as in his or her mind, my disability meant I was uneducated.

I am now a pensioner and receive 100 Euros per month. As you can imagine I cannot save any money. It becomes a nightmare when I need to renew my prostheses as only 80% of the expenses are covered by the state, with the balance to be provided by the customer. My contribution was to be 6000 Euros. Impossible! Over three years, I went to 100 companies and NGOs to find sponsorship. It took me three years. But I now have a new leg and arms!

I can do everything on my own. I just need some help to get dressed. My neighbours are always here to help me.

I just wish that all people with disabilities could live the same life as mine. Life is so beautiful!

5. EDUCATION: FROM SEGREGATION TO INCLUSION

UN Standard Rule 6. Education (extracts)

States should recognise the principle of equal primary, secondary and tertiary education opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system.

• To accommodate educational provisions for persons with disabilities in the mainstream, States should:

- Have a clear stated policy understood and accepted at the school level and by the wider community,
- Allow for curriculum flexibility, addition and adaptation,
- Provide for quality materials, ongoing teacher training and support teachers.

The Salamanca Declaration on inclusive education states⁴⁴ "[...] *regular schools with an inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all... and ultimately the cost-effectiveness of the entire education system*". In order to reach this goal, the education system has to be adapted not only in regards to physical accessibility, but also in terms of flexibility of curricula and adaptation, support to, and continuous education for teachers and access to supportive devices for the children. For the situation in South East Europe, where the general context is not yet able to meet the needs for all people with disability, some special educational structures may be needed in a transition period, but with the aim of preparing pupils for mainstream education.

5.1 Legacy and current context

Under the previous system in former Yugoslavia, education was considered a priority for all able-bodied citizens and was therefore given the necessary financial and technical means to support high enrolment rates. The situation in Albania was similar. Enrolment rates in the region were relatively high, between 80-85% according to UNICEF⁴⁵. During the transition however, public expenditure on education decreased, and especially in the countries exposed to conflict, the quality and condition of schools decreased quite dramatically⁴⁶. The education system in former

Yugoslavia was quite centralised, even though in theory self-management allowed for some autonomy for the municipalities, it was characterised as rigid and non-flexible. A concept of "production of workers" and a strong orientation towards professional education were embedded in the education system and since people with disabilities were not seen as productive, the inclusion of children with disabilities in mainstream education was not a priority. Theoretically, children with disabilities could be included in regular school, but the law did not explicitly mention this as a right, and therefore it was not considered as an option for either teachers or most families.

All countries in South East Europe have signed and ratified the UN Child Rights Convention that states that all children have the right to compulsory and free education (Article 28), and where Article 23 enforces this right especially to children with disabilities. Despite reforms that have been undertaken, the legacy of the old system of education is still very much present. Several reports by UNICEF, Save the Children and other national and international stakeholders, show that most children with disabilities are still unable to exercise the right to education in most of the countries in South East Europe⁴⁷.

Primary educational system

A system of segregated special education, similar to that in Western European countries in this period, was developed throughout the region. It followed the philosophy that children with disabilities needed

⁴⁴ Salamanca Statement on Principles, Policy and Practice in Special Needs Education: "Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; more over, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system"

⁴⁵ UNICEF, "Social Monitor 2002 - Social Trends in Transition, HIV/AIDS and Young People, Quality of learning in School" (Florence: UNICEF Monee project, 2002).

⁴⁶ UNICEF, "Generation in jeopardy, Children in Central and Eastern Europe and the former Soviet Union" (New York: UNICEF, 1999): 49-51.

⁴⁷ UNICEF, "Report of the result of the participatory research on poverty affecting children in Montenegro," (Podgorica: UNICEF, 2003); Inclusion Europe, Human Rights for Persons with Intellectual Disabilities - Country report Bulgaria" (Brussels: Inclusion Europe, 2001); UNICEF, "Comprehensive Analysis in Primary Education in the Federal Republic of Yugoslavia" (Belgrade: UNICEF, 2001); S. Hrnjica, D. Sretenov, "Children with Disabilities at Mainstream Primary Schools of Serbia - Current State and Attitudes Prerequisite for Potential Inclusion," (Belgrade: Save the Children UK, Serbia, 2003).

specialised education together with their peers and that they would not benefit from schooling within the regular system. The special education system is designed for mild to moderate levels of disability, and linked to the specific type of impairment, and most of the schools have a boarding school approach to accommodation. Children with more severe intellectual disabilities, or those with multiple disabilities, were generally considered as "non-educable" and therefore directed towards social residential institutions or stayed within the family. Social residential institutions are still managed by the Ministry of Social Affairs, which has no formal links with the Ministry of Education and therefore no formal education is offered to beneficiaries in these institutions.

In the education system, the teaching approach could be described as "closed and conservative and having little contact with the social welfare and healthcare systems or the community [...]". Schools remain driven by teaching instead of learning⁴⁸. This became even more obvious in the system of special education, since the work was mainly oriented towards functional rehabilitation and optimising the intellect of the child, rather than on developing the capacity of the child to integrate into social life. Children with severe disabilities were therefore systematically excluded since it did not appear relevant to attempt to remedy the impairment.

In Albania, the situation was quite similar to former Yugoslavia. Families preferred to send their children to special schools due to lack of information and/or fear that their children would be abused or neglected within regular schools. Today there is a demographic shift in Albania due to extensive migration to larger urban centres, especially Tirana, as well as emigration abroad. Thus many schools in remote areas are closing as a result of reduced enrolment, meaning children have to travel further to school. This affects families with children with disabilities in particular. According to a report published by Save the Children Albania, there is a need for a whole new re-building program since schools have been destroyed, become overcrowded and are not at all accessible for children with disabilities⁴⁹. Teachers in the special education system in Albania have few contacts with local authorities as the system is administered directly by the Ministry of Education. This brings about some inequalities in terms of continuous training, existence of quality indicators as well as updating of curricula⁵⁰.

Secondary and higher education

Children with mild disabilities are mainly directed towards secondary schools for vocational training, the aim being finding a profession afterwards. This system

is to a wide extent designed in the same way as the primary education system; children with disabilities are segregated based upon the category of disability. Opportunities to access vocational training are based on type of impairment and level of disability and not according to abilities or personal wishes. Often, students that attended special schools just continue "across the schoolyard" into vocational secondary school. The possibility of enrolment in university is very limited since no university is designed to accept people with disabilities, and only the most persistent, with support of family and friends may achieve a higher education in this system. In Albania, the access to higher education was available only to students with a visual impairment or slight physical disability.

Today the system of special vocational education faces problems of inadequacy of vocational training programmes for people with disability as they are based on the "old economy" and subjects are related to manufacturing and processing jobs, while people with visual impairments are trained as switchboard operators. These are outdated professions with low competition profiles⁵¹.

5.2 Initiatives for change

Most legislation on education in the countries of South East Europe has undergone certain reforms and the new laws underline free education for all children and to certain extent the issue of inclusive or integrated education. In reality though, there are no legal enforcement mechanisms or even resources

Pledges regarding the Inclusion of children with special needs at all levels of the education system in Bosnia and Herzegovina

- Assess the number of children with special needs and the difficulties they face in order to determine the challenges that impede their inclusion into the general classroom (December 2003),
- Develop a plan to educate the community (including school boards, teachers, parents and students) with respect to the inclusion of children with special needs at all levels of the education system (August 2005),
- Revise the current classification system for children with special needs to ensure that contemporary principles of inclusive education are followed (2003).

⁴⁸ UNICEF, "A Brave Generation Youth in Federal Republic of Yugoslavia - Findings and Recommendations" (Belgrade: UNICEF, 2002).

⁴⁹ Save the Children, Albania, "I am like you: An investigation into the Position of Children with Disabilities in Albania," (Tirana: Save the Children, 2003).

⁵⁰ Save the Children, Albania, *ibid*, 66.

⁵¹ In Macedonia, 40% of the vocational training is in the "old economy", and 13% in manufacturing and processing according to UNICEF report Situation Analysis of Children and Families in Macedonia, (UNICEF: Skopje, 2000).

available to support teachers, to adapt curricula, to make schools accessible or to work on the existing prejudice by teachers and communities towards inclusion.

One of the main entry points into the education system for children with disabilities are the "Commissions for Categorisation" that existed, and still exist, in various forms throughout the region. These commissions are usually based in Health Care Centres or Centres for Social Work, but were under the jurisdiction of the Ministry of Education. The objectives of these commissions are to provide a diagnosis of the child's impairment and recommend a special programme of education in order to "correct" the deficiency. This usually takes place at the age of six to seven, meaning that early intervention for minimising the consequences of disability and preparing the child for education is largely neglected.

One interesting reform initiative of this "categorisation system" has been made in Serbia and this can be further followed in part III chapter 4.1.

Inclusive education - initiatives of reform in Bosnia and Herzegovina

Bosnia and Herzegovina (BiH) has introduced inclusive education based on a partnership between central and local government and the NGO sector, a reform where children with disabilities are included using

a mainstreaming approach (Box 15). In late 2002, the Ministry of Education of Republika Srpska, the Ministry of Education of the Federation of BiH and Department of Education of Brcko District, signed an Education Reform⁵². Amongst the pledges of the Ministries in the Education Reform, there are several on inclusions of children with disabilities⁵³.

In Albania, general reform on education is on-going, mainly to improve teaching methods and curricula, and to introduce inclusive education through the following principles⁵⁴:

- All children have the right to attend school near their home,
- Schooling opportunities should not be designed on the base of the type of disability, but on the individual needs of the child,
- All teachers can teach any child, no matter of the type of disability with adequate training and support,
- Despite the parents, children have as well the right to decide on their schooling.

International stakeholders - implementing pilot projects of inclusive education

The Save the Children Fund (SCF), along with UNICEF, are few of the international actors in the field of promoting inclusive education in the region

BOX 15

Project of inclusive education in Bosnia and Herzegovina - example of collaboration between NGOs and the state

DUGA, a local NGO in Sarajevo working with children and youth in difficulties, in partnership with OSCE, Federal Ministry of Education, Ministry of Education in RS and the Pedagogical Institute of Banja Luka, implemented a project on inclusive education in 16 school districts in Bosnia and Herzegovina in 2002. The results of the project were developed into a "Model of inclusive education". This has become an integral part of the Strategic document for Reform of Education System in BiH".

This project provided an opportunity to analyse the sustainability of inclusive education. There were 444 pupils with disabilities involved in the project in 16 school districts, and teachers received training and support on inclusion prior to and during the project. The implementation of inclusive education in these 16 school districts met certain constraints in terms of prejudice among teachers and families, lack of supportive material and expert teachers as well as reluctance among parents of the children with disability

The sample of 16 school districts provided good results:

- 95,3% of teachers thought that it is possible to implement inclusive education under the conditions given through the project,
- 96,1% of parents expressed high level of satisfaction and gratitude for experts' support,
- None of 444 children went through the process of categorisation but it was proposed that 12 out of 444 were to be placed in special classrooms as partial integration.

Source: H.O. Duga, "Inclusive Education for Children with Special Needs in Bosnia and Herzegovina - Final Report," (Sarajevo, Bosnia and Herzegovina, January 2003): 4, 8-21.

⁵² Ministry of Education of Republika Srpska, the Ministry of Education of the Federation of BiH and Department of Education of Brcko District, education reform mandate, "A Message to the People of Bosnia and Herzegovina, Education Reform," 21.11.2002

⁵³ Education reform mandate, *ibid*, 10-13.

⁵⁴ Part of the Normative Dispositions in the Law on Pre-university Education System, no. 7952, 21.06.1995. These laws have not yet been implemented.

BOX 16**Save the Children UK, Serbia and Montenegro**

Save the Children's (SCF) activities in South East Europe started during the conflicts and economic crises between 1996 and 1998. During this period SCF opened offices in most of the countries in the region, working on the issues of education for children with special needs or other marginalised groups. During the two last years, SCF has made the transition from emergency aid towards a long-term development approach in their projects. In addition, they are developing a regional approach to the Inclusive education projects, trying to harmonise their methodology and to share knowledge and experiences.

Initiating inclusive education in Serbia and Montenegro

In Serbia and Montenegro their project of Inclusive education started seven years ago with the creation of an inclusive pre-school in Podgorica. It started with a small pilot project where a small number of children were included in mainstream pre-school and simultaneously teachers and representatives from local authorities were trained on disability. After one year of piloting, this method was applied throughout major municipalities in Montenegro, and today SCF claims that local authorities and ministries are able to apply this method, with support of resource groups of teachers for the rest of the country.

The main difficulties during the implementation of inclusive education were the negative attitudes towards children with disabilities, among teachers, the majority of whom previously considered children with disabilities as "non-educable", and among families of children with disabilities themselves. There is a big job needed of awareness raising on the holistic and social model of disabilities for all stakeholders in the communities.

Legislative impact

Save the Children took an active role in lobbying the Ministry of Education in order to develop a strategy for inclusive education in the Republic of Serbia. This strategy has been accepted, although with less emphasis on inclusive education than initially aimed for. The strategy acknowledges the right to education for all children, including children with disabilities. While the inclusion strategy is positive, it does not include any enforcement mechanisms for implementation and there are no provisions for training teachers on disability or adapting the classroom for children with disabilities.

(Box 16). Since 1997 SCF has worked in Serbia and Montenegro on introducing the approach of inclusive education in pre-schools and supported Associations of parents of children with disabilities. Their experience shows a good approach to changing the attitudes of professionals as well as families and children. These stakeholders were also influential in the new education strategy defined by Ministry of Education in the Republic of Serbia, where inclusive education is addressed.

In Macedonia, several initiatives for integrated and/or inclusive education have been made, but without a coherent strategy from the Ministry of Education. For example, the Bureau for Development of Education is engaged in an on-going project for integration of children with disabilities (pre-school age) in 13 kindergartens in Macedonia, co-financed by UNICEF and supported by the Ministry of Labour and Social Policy.

Day Care centres filling the gap of access to primary education

Many of the newly developed Day Care centres in the region have included an education component in their programmes. In fact, some of them have developed their activities mainly in the direction of adapted education as they have recognised the lack of these

services for children with severe disabilities. Often, the educational activities are combined with training in the skills of daily living, which is more important for some children as it allows them to gain more social skills and greater autonomy and independence.

One example of good practice in this field is that of **Aurora Day Care centre/ASCHF-R** in Bucharest, Romania. Aurora has been providing education to children with moderate to severe neuro-motor disabilities since 1995. Their initial objective was to provide opportunities for education of those children with severe disabilities in Bucharest without access to any education services. Over the years though, while succeeding to integrate several children into special school, and some into ordinary schools, Romanian society has become more open to inclusive and integrated education, and the mission has slowly changed to one of preparing children to be included into regular schools to the widest extent possible. A closer description of Aurora Day Care centre/ASCHF-R is found in the spotlight at the end of this chapter.

5.3 Looking ahead

As presented earlier, certain initiatives for improving access to education for children with disabilities, both on the legislative and pilot project level have

been implemented throughout the region. The main obstacles to inclusion and integration have been shown to be:

- Prejudice and lack of knowledge on disability by teachers and among children without disabilities and their families,
- A lack of specialised support to teachers in mainstream education,
- No legal enforcement mechanisms to push for inclusive education,
- Resistance among professionals in the special education system.

Process of inclusion

- **Inclusion must commence while the child is still at an early age and the child should mix naturally with its non-disabled peers in nursery care and kindergartens,**
- **Children should have access to preparatory**

and additional support prior to entering mainstream education. In a transition process this could be provided within community-based programmes, such as Day Care centres while working on mainstreaming regular educational systems,

- **Disability has to be mainstreamed within teacher's education,**
- **Defectologists and special educators should develop more into support- and reference persons⁵⁵.**

Finally, the access to higher education is another crucial issue in terms of gaining competitive skills for young people with disabilities in order to have equal access to employment later on. Here the role of student associations is crucial, and as shown in the spotlight on Association of students with disabilities in Serbia their lobbying has proven to be very efficient.

⁵⁵ More information regarding the reform of the special education system in Norway can be found within the Service catalogue: "Special education services from the Norwegian Support system for Special Education," (December 2003) available at: www.statped.no

SPOTLIGHT 3

AURORA DAY CARE CENTRE IN BUCHAREST ROMANIA

Objective of Aurora Day Care centre

The Day Care Centre Aurora is the only centre in Bucharest providing scholastic educational and rehabilitation services for children with neuro-motor disabilities aged from 5 to 14 years. The centre was created in 1995 and is the result of the partnership between the Support Association for the Physically Disabled Children from Romania (ASCHF-R) and the International Humanitarian organisation Handicap International. The main objective for the opening of the centre was to provide activities for children with severe disabilities, without any type of support and kept at home within the families.

Partnerships and activities

Since 1996 Aurora has been integrated into the national system of special education. The Ministry of Education funds teacher salaries. Aurora's other major partners are: the Ministry of Labour and Social Solidarity and the National Authority for Disabled Persons and Romanian and foreign NGOs.

Services provided in the Day Care centre component:

- Education according to adapted curricula in small groups (4-5 children/teacher) where each child is learning in accordance with their specific abilities and needs,
- Physiotherapy and speech therapy services on a weekly basis,
- Counselling to families of the children included in the centre,
- Preparation for integration into special education and mainstream education.

Continuous development of the activities according to the needs of the community

In 2003, the parents of children who completed the education segment with Aurora requested the establishment of a Sheltered workshop. A project, aiming to provide a range of services for young adults on their path towards integration in the job market was planned. The workshop opened in 2003 and is being developed in line with the needs of the beneficiaries of the centre. The idea is that the centre can provide job opportunities for youth that cannot be integrated in the open labour market. It also functions as a training centre and transition point for some youngsters who are capable of finding a suitable job in the open labour market. A programme providing training in daily life skills for teenagers and young adults with severe disabilities is included in the workshop's activity plan.

The third and final component of Aurora is the Resource Centre, which was a natural development from the Day Care Centre. The aim is to better support families and to address an increasing demand from other stakeholders in the de-institutionalisation process in Romania in terms of professional training and practical internship. Today the resource centre has become a place where families come for advice and information on all topics relating to physical disability. Here also, a well-trained team of professionals can provide training and consultancy to other institutional stakeholders, NGOs and governmental bodies on alternative support to children with multiple disabilities and also on management and approaches to disability and inclusion.

Organisational development of Aurora

Aurora has shown an interesting development during the last period and in the way they ensured the sustainability for their services while still adhering to their mandate and values. Their adaptation to the changing legal environment, to the decrease of international funding presence, to new emerging needs of the community in which they provide their services, can give some indications that seem necessary for the survival of such NGOs:

- Strong leadership skills in management positions,
- Motivated and flexible staff,
- Wide network with local stakeholders such as municipality, local companies, local educational structures, other civil society organisations, parents associations, different ministries and international NGO's and donors,
- Quality of the services provided (internal manual of procedures in accordance with new legislation in the field of standardisation and accreditation, annual evaluations and needs assessments of all beneficiaries involved in Aurora's programmes etc.),
- Diversity of type of financial donors,
- A clear strategy of development of the services, according to the results of permanent needs assessment of all beneficiaries,
- A strong partnership with the families of the children with disabilities, in all the current activities, but also in the development of the day centre services.



*Aurora
Day Care centre,
Bucharest*



Life story 3: Finding support in order to complete education successfully, from Kosovo

My name is S. I was born on 7 May 1981 in Pristina. My parents told me that my deafness resulted from a fever I had when I was 2 months old. They sent me to the doctor immediately for treatment but they weren't told that the fever could have tragic consequences. At first my parents didn't realise anything had happened but with time my behaviour showed that I couldn't hear. Once my problem was identified they started to look for further treatment. They spent many years and much effort trying to find a treatment for me, with referrals to many doctors. No parental support group existed at the time so my parents had to find their own way. They placed all their hope in doctors, who in reality couldn't provide much support to my parents or me. From age three months my parents were always looking for the treatment and so they sent me to other medical centres of ex-Yugoslavia, such as Skopje (Macedonia) and Zagreb (Croatia) in the hope that they could help me to hear again. These were very hard times for my parents because they were living in a world of prejudice and laggard mentalities where it was considered disability was a punishment from God for the entire family. I was lucky however, because my parents were educated and they didn't care what others say and think. They never lost hope and never stopped looking for a cure.

My father was the director of a kindergarten and I was placed there from age 8 months to 7 years. I completed my preschool level there as well. My parents didn't mention having any problems placing me in kindergarten but that may have been because of my father's position. The kindergarten was not prepared for children with disability as the building was not equipped and adapted nor was the staff sensitised and trained to work with them. The presence of my father helped me very much as the only way I could communicate with the teacher and the other (non-disabled) children was through him. At first there was nowhere my parents could learn sign language so we had to invent our own way of communicating.

When I was 7 years old my parents registered me at the special school for deaf people in Prizren. It was first time that I was leaving my house for the longer period of time so it was not so easy for me. At the beginning of my accommodation in the special school, I couldn't understand why I was there and what was going on around me. I couldn't speak Sign language so it was difficult to understand the teachers. In the school I met for the first time other children who were deaf as well. For the first time I felt myself equal with other children and I noticed that I'm not "alone" in this world. Until then I had only been with children who were different from me because they could speak. The teachers at the school were very kind and gradually I started to adapt myself in the new environment. In the beginning my parents hesitated to leave me at the school, because they were afraid that I would miss the proper care there.

Fortunately very soon they were ensured that they were wrong and I think that decision taken from them to attend the school has opened the window of the success in my life. I attended education there for one year but then returned to Pristina where I completed my primary education. The school I attended had a special class for deaf pupils. I was happy because I was going back to Pristina and again I was with my family. But same time I was sad because I had to leave my second family I already created in the school in Prizren. In Pristina it was much more difficult to adapt because of the fact that in the school were not only deaf pupils as it was the case in Prizren, but there were also other "normal" pupils attending the school as well. The differences between the deaf and the non-deaf pupils were evident because all of us were in the same school and we couldn't communication amongst each other. I and other deaf pupils were not able to speak the speaking language and in other side the other non-deaf pupils were not able to peak the sign language. Because of that very often we had conflict situations among each other. Very often other pupils were making fun of us, but we were also making fun of them.

Now very often I ask myself - who was making fun of whom indeed?! The teachers made a lot of efforts to educate other children in terms of sensitivity towards pupils with disabilities, but they were missing the training and sensitisation toward disability for themselves as well. After I finished my primary education I went back to Prizren to continue my secondary education in a special school for deaf people.

Even now it is considered that deaf people can only be trained for handicraft but not for any professions requiring intellectual capacity. I have faced this discrimination as a deaf person and I would like this attitude towards deaf people to change. I wanted to prove that deaf people could also be intellectuals with a university education.

After I completed secondary school I became active in a deaf club in Pristina. This club was another opportunity for more successful communication with society in general. Through the activities developed there I had an opportunity to meet many people who made a big impact on my future and on helping me to reach my goals. Amongst the many people I met were representatives of the Finnish Department of Education. They supported me in my dream of attaining a university degree. With their financial support I'm now a final year student of the pedagogic faculty at Pristina University. I will be the first deaf pedagogue with a university degree and I'm deeply convinced that I will not be the last one.

SPOTLIGHT 4

ASSOCIATION OF STUDENTS WITH DISABILITIES IN SERBIA

Access to Higher Education: Association of Students with Disabilities (ADS) in Serbia

Established in 2000, ADS is a cross-disability, inclusive organisation of persons with disabilities that struggles for the realisation and respect of human rights and equalisation of opportunities for young persons and students with disabilities by creating conditions for inclusive formal and informal education and application of the social approach to disability. ADS' main activities are:

- Media campaigns (five successful ones so far)
- Counselling (medical, psychological and psycho-social support)
- Educational seminars, trainings, workshops, and summer school
- Equal opportunities scholarship program (lasting for over three years with over 120 users)
- Employment empowerment programme for young persons with disabilities (computer classes, foreign languages courses, and training on various skills)
- Lobbying for changes in legislation in order to create optimal conditions for education of persons with disabilities as well as amending laws that help facilitate full participation,
- Adapted transportation projects and those related to services for young persons with disabilities

Assistance to Inclusive Education project

The Association of Students with Disabilities in Serbia began a programme in 2001 called Assistance for Inclusive Education to support students with disabilities attending university.

The programme has four components:

- Scholarships for the equalisation of opportunities under the Ministry of Sports and Education,
- Adaptive transportation taking students with disabilities to exams,
- Assistance to students making appeals to their university administration and management for obtaining their rights and greater accessibility,
- Counselling to encourage and empower students with disabilities to be pro-active in obtaining a higher education.

Scholarships

Each year, the Ministry of Sports and Education gives scholarships to university students with strong academic records. The eligibility criteria are rigorous and strict, one of the conditions being regular attendance for the full academic year. These kinds of criteria do not take into account the challenges and obstacles students with disabilities face in a non-adapted and non-inclusive educational system. The Association of Students with Disabilities lobbied with the Ministry of Sports and Education to lower the eligibility criteria for students with disabilities applying for the scholarship in an effort to equalise opportunities. As a result, the Ministry of Sports and Education changed the eligibility criteria for students with disabilities to be:

- The student must have a disability,
- The student must attend a state funded university, and their studies must be state funded
- The student must be currently attending university at the time of their application.

Transportation service

The initiative includes an adaptive transportation service to take students with disabilities in an adapted van to their exams, medical appointments, or important events or meetings at their universities. The transportation service does not have the capacity to provide regular service to students.

Guidance

The third component of the programme is **guidance** to students with disabilities making appeals or demands to their university administration for **more accessibility**. A critical obstacle for students with disabilities face is that lectures, exercises, exams and the like are often held in rooms that are inaccessible so they are often unable to fulfil their academic obligations. The Association helps students to write letters to university administrators asking to change the location of exams to an accessible facility. The aim is two fold; on the one-hand, this initiative helps students to advocate for their rights while promoting awareness raising on accessibility issues within higher education.

Counselling on empowerment

Finally, the fourth element of the programme is counselling on **empowerment**. The aim is to teach young people with disabilities to be pro-active in obtaining an education emphasising that attending university is achievable. This counselling is conducted either in individual psychological support sessions or group counselling in the form of workshops.

Next Steps:

The Association of Students with Disabilities in Serbia is currently developing an assistance programme to support students attending university. The project will differ from a personal assistance programme in that it is aimed specifically at supporting students with tasks related to completing their university degree such as, note taking, assisting with translations into Braille, and support during exams, which could be organised through applying civil service on universities.

6. VOCATIONAL GUIDANCE AND EMPLOYMENT: FROM SHELTERED WORKSHOPS TO MAINSTREAM EMPLOYMENT

UN Standard Rule 7. Employment (extracts)

States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.

- Laws and regulations in the employment field must not discriminate against persons with disabilities,
- States should actively support the integration of persons with disabilities into open employment. This support could occur through a variety of measures, such as vocational training, incentive-oriented quota schemes... [..]

Through well-designed vocational training programs, incentive-oriented quota schemes, loans or grant for small business, tax concessions or other technical and financial assistance people with disabilities could have a better access to employment in the job market. Only if the needs of the person with disabilities cannot be met in the open market should supported employment or small units of sheltered employment be an alternative.

6.1 Legacy and current context

The move from the concept of full employment through a state based economy towards privatisation and a market economy has resulted in a rapid increase in unemployment in all countries in the region. According to the UNICEF Social Monitor of 2003, the unemployment rate in the countries of South East Europe is not showing any significant decrease and women in particular have been the main losers in the shift to a more competitive labour market⁵⁶. This indicates that the situation for people with disabilities, especially women, is becoming increasingly difficult in terms of employment.

Vocational guidance and training

The main opportunity for vocational training during the previous system of former Yugoslavia was within secondary schools (as described in the previous chapter), and thus only available for young adults with mild disabilities. One of the main obstacles to integration into the open labour market was that the 'Employment Bureau' did not deal with the issue of unemployed persons with disability. Centres for Social Work were responsible, reinforcing the idea that people with disabilities are not a fully-fledged

component of the work force, but more in need of some kind of activity.

Employment

The employment system for people with disabilities in former Yugoslavia has been described as "a system mainly based on sheltered workplaces without any provision for a quota system or reasonable accommodation approaches⁵⁷". The main option was (and is still the case in some countries) to enter a sheltered workshop, which was decided on by a medical commission in the Centre for Social Work. A person who acquired a work related disability as an adult could be rehabilitated within a sheltered workshop, and then re-integrated into his/her former employment. If this was not possible then the person would be granted an invalid pension. In theory, according to the legislation each employer has an obligation to employ persons with disabilities and to provide them with adapted workplaces. This rarely happens in practice because of the lack of enforcement and complaints mechanisms.

It should be noted that in Albania, no system of sheltered workshops has been developed, and the main opportunity for persons with disabilities to obtain work was by way of personal contacts and support, despite the existence of supporting legislation, again without enforcement mechanisms⁵⁸. The previous system had a strong philosophy of producing workers, "the communist concept of the ideal citizen - a healthy manual worker- reinforced the negative image of people with disabilities and label them as misfits," according to a Disability Rights Advocates report published in 2001⁵⁹.

⁵⁶ UNICEF, "Social Monitor 2003: Economic Growth and Poverty, External Public Debt, Refugees and Displaced Persons, Inter-Country Adoption, HIV/AIDS," (Florence: UNICEF Monee project, 2003).

⁵⁷ Branko A. Lubarda, "Final Report on Law on Employment of Disabled Persons," (Belgrade: January 2003).

⁵⁸ In the specific laws for each disability it is stated that the disabled workers should have an adapted job, according to their working capacity and one out of 24 employees should be a person with disability.

⁵⁹ Disability Rights Advocates, "Invisible and neglected: Status of the Human Rights of People with Disabilities in Central Europe," (Disability Rights Advocates, 2001).

6.2 Initiatives for change

State reforms and initiatives

The legacy of the old system of sheltered workshops and protected employment still underpins policies and initiatives for employment and they are still the main options for employment of people with disabilities. There are basically no opportunities for the person with more severe disability to earn a living and thus have a better chance to integrate in society. Macedonia is one of few countries that have initiated certain legal reforms in terms of incentives and tax exemptions for employers as well as the creation of a Special Fund that can be used for providing favourable working conditions for people with disabilities. Also worthy of mention is that in the UN administered province of Kosovo, the Ministry of Social Welfare and Labour recently increased support for vocational training for people with disabilities. New ordinary vocational training centres have been established in seven municipalities throughout in the UN administered province Kosovo where disability has been mainstreamed to a certain extent. With the support of the International Labour Organisation (ILO) staff has been trained on assisting people with disabilities. The following training courses are available as well for people with disabilities: textile, cooking, metalworker, joinery, construction and business/ administration.

Vocational training and sheltered workshop as a pilot project in Romania

Aurora, the Romanian NGO mentioned previously, has recently initiated a sheltered workshop project where vocational training skills are addressed as well. Young adults are being trained in individually designed programmes of computer skills, pottery and candle making and they are supported in the process of entering the open labour market. People who do not have the possibility of being employed may be offered a job in the sheltered workshop.

This programme is in compliance with the UN Standard Rules as well as Council of Europe Recommendations and should as such be subsidised by the local or

national government in Romania⁶⁰. The mechanisms for implementing sub-contracting and accreditation systems are still missing, however one positive development is that the Romanian Government has recently passed a law that recognises this type of service.

Supported employment in Zagreb and Timisoara for persons with intellectual disabilities

The Association for Promoting Inclusion (API) in Zagreb, Croatia, has developed a programme of what they call 'Supported employment' (Box 17). This programme started as a project in 2000 as support to an on-going project of re-integration of people with intellectual disabilities from residential institutions into the community by providing opportunities for independent homes and access to employment.

The programme of "Supported employment" presented a significant challenge in the start-up phase, considering the general situation in Croatia, such as high unemployment, prejudice, the absence of legal framework and limited financial support. Nevertheless the results have proved surprisingly positive. This experience is extremely valuable as these difficult pre-conditions exist throughout the region and are often used as an excuse in order to escape responsibility. The experience in Croatia with API shows that it is possible to work on the issue of mainstreamed employment, the most crucial part for integration and equal opportunities for people with disabilities.

Another interesting experience regarding supported employment is being implemented by **Pentru Voi Foundation** in Timisoara, based on a similar methodology as API. Their experience is presented as the spotlight of this chapter.

Income generating projects managed by DPOs - working for official recognition

In the previous system in former Yugoslavia, several sheltered workshops existed, often managed by Unions of organisations of people with disabilities, where 40% of the workforce was people with disabilities. In

BOX 17

Result of Association for Promoting Inclusion's programme of supported employment in Zagreb, Croatia

The Association for Promoting Inclusion (API) started this project by exploring the private and public job market and initiate contacts with companies and institutions that would be interested in such collaboration. The results showed that mainly international companies were positive to such partnership, while national companies were more sceptical and reluctant. Up to today, **20 people** with intellectual disabilities have found employment. API provides the employees with a 'job coach' that provides support on-the-job during the initial process and the persons have the opportunity to ask for support continuously during their employment. One of the key issues for the positive results reached by API is their wide network within the public and private sector, as well as their credibility in the field of working with people with intellectual disabilities.

⁶⁰ Council of Europe Recommendations R (92) 6 No. 9

the last decade most of these companies have been destroyed, lack financial support from the state or are highly corrupted. In Serbia and Montenegro however, several DPOs have re-started employment activities for their members in the form of income generating projects. Thanks to micro-grants from various donors, several small businesses such as photocopy shops, printing companies, transportation companies; as well as computer design and PC courses have been initiated. The main difficulty however is that there is no legal framework for NGOs or DPOs to set up companies and to have access to incentives like lower taxes, which is why many companies are not officially recognised at this stage.

Dunav, the Association of paraplegic and quadriplegics in Belgrade has been lobbying the authorities for a long time to have their photocopying company recognised and their workers employed as regular employees. Once this has been achieved, their experience and success can be used by other organisations wishing to create similar opportunities for people with disabilities.

6.3 Looking ahead

There is a need for complete reform in the field of vocational guidance and training throughout South East Europe. One of the key issues for people with disabilities achieving equal opportunities for an independent or autonomous life is the provision of further employment opportunities. The current system of vocational training and guidance is based on an outdated approach of sheltered employment and training based on medical diagnosis rather than choice

and abilities. As discussed in this section, there are also limited pilot experiences in the region that mainly address emerging needs within a certain community, but not the system as such.

Various experiences show that it is possible to have a positive impact on access to employment without major investment and resources however, as shown by the examples of the Association for Promoting Inclusion in Zagreb and Pentru Voi Foundation in Timisoara.

The main priorities in the field of access to employment should be:

- **Vocational guidance should be part of the regular employment bureaus where staff is sensitised on disability,**
- **Vocational training facilities for people with disabilities should provide competitive trainings and as such give opportunities for real employment afterwards,**
- **Different incentives should be provided to employers to hire people with disabilities,**
- **Awareness raising campaigns to overcome prejudice regarding workers with disability,**
- **Increased collaboration between DPOs and Unions of workers organisation in order to mainstream disability in these organisations.**

During the transition period, as well as for some persons with disabilities whose needs cannot be met within the regular employment market, a system of sheltered workshops will still be needed.

Life story 4: Sheltered employment companies - murky business, from Macedonia

Milan has worked for three companies that employ persons with disabilities, yet after time, he became disappointed. Why? This is his story...

I was born and live in Skopje. I have a slight physical disability, which has a slight effect on my ability to work. As I am relatively big and strong, employers look at me and think: "This man is good for physical work, plus I can get good money from the government if I employ him".

My employment odyssey started 9 years ago. After completing secondary studies, I found work as a security guard with a company called 'Cao-Cao', but I didn't work there officially for even one day. The owner stalled me, telling me I'd be officially employed soon but after many promises nothing happened.. He only paid me 50 euros for the work I'd done unofficially, assuring me that I would receive the rest once I was officially employed, but they kept me hanging on for another 7 to 8 months, until I saw nothing would come of it, so I resigned. 'Cao-Cao' was a construction company and that employed persons with disabilities and thus, they received some benefits from the government.

After being unemployed for some time, I found work with a company called 'Expert'; another sheltered employment company that deals in air compressors. At first things went well, I was officially registered as an employee and received a health care card. All employer contributions were paid but problems started after a couple of months when the employer sent me on compulsory leave. After that I was sent on compulsory leave every 2 to 3 months. My regular wage was 8000 Denars per month but I only received 2000 Denars whilst on leave. I think the employer was expecting a government grant to refurbish his plant but he would send me on leave from time to time while he was waiting.

After a certain amount of time when I saw that out of almost two years employment, I had been on compulsory leave for 9 months, I decided to resign, as I saw no future in such a situation.

The third and last company was called the 'Furniture Centre', which had a factory in Zelezara. Mr. Momir Stratevski, the owner, found potential new workers through the Association of Physical Invalids. There was no explanation why but he asked that I agree to upgrade my qualifications with the Employment Bureau in order to get a promise of 6000 Denars pay and 3000 Denars for transport and food, per month.

Twelve people from the Association of Physical Invalids accepted the offer, but we stayed at home for the three months while we were supposed to upgrade our qualifications while the owner had to set up the factory to adapt the workplace for people with disabilities. He didn't explain that the training was on-the-job and that there was no need for the three-month re-qualification period. While we were sitting at home, it seems that he got the government grant and started with the work. In the first few months he paid out only part of our wages, with the promise that the balance would be paid out in the next period. Nevertheless, this did never happen. And so it went for one whole year.

During that period I injured my finger. Thank God I didn't lose it. The owner told me; "Don't come to work until you've recovered!" I didn't go to work for two weeks and made the mistake of not going to a doctor to obtain a medical certificate. My absence wasn't treated as sick leave and so I was considered as simply not coming to work.

For the entire period of one year I was paid a total of 15,500 Denars, which doesn't add up to even two pays according to the agreement.

Leaving without an employment record

I could see that nothing was happening, that the man did not stand behind his words, only giving promises he could not keep, and yet I think he received 3500 euros for each person with disabilities he employed, plus a grant to upgrade his factory and of course, tax relief.

In the meantime I asked to return to the 'Expert' company considering conditions were more or less okay there. I made a verbal agreement to do so but there were problems in switching from company to company. The owner of 'Expert' wasn't sure that he'd get a government subsidy for me but I wanted to see whether he considered me to be a person looking for work or simply a means of getting government money. In the end he saw that he couldn't get the 3500-euro grant, so he brushed me off.

In the meantime, I decided to get my employment records book from the 'Furniture Centre' but the owner wouldn't give them to me, so I reported him. I gave a statement that he didn't pay me the agreed amount and so I had decided to resign.

What struck me hardest was that the boss of 'Furniture Centre' thought my injury at work was insignificant, just a small cut and that I allegedly voluntarily didn't come to work for two weeks.

When the inspectors visited the owner of the company, he mucked them about for a month after my resignation before finally reporting it. He gave the inspectors my resignation papers, falsely showing he had paid me 5000 denars per month.

After that I went to retrieve my workbook from the Employment Office but they informed me that I had agreed that I would refund the retraining grant of 12,000 denars if I left work within 12 months. Now the officials at the Employment Office were threatening to take me to court to retrieve the money. When I went to get my workbook I had to make a written statement that I would refund the Employment Office for my so-called "retraining" when my former employer finally paid me what I was owed. I asked 'Justiciana', Polio Plus's legal aid service for assistance and now I'm waiting for something to happen. Hence my opinion that sheltered employment companies are murky businesses. Many companies that consider starting sheltered employment see people with disabilities simply as a means of getting government funding. If at least that money was used to improve working conditions and ensure decent pay for people with disabilities.... but that rarely happens. My experience to date leads me to conclude that these sheltered employment companies are just 'smoke and mirrors' and I'd be reluctant to work for such a company again.

Vulkan n. 11, March 2003, Skopje, Road Works, article by Dusko Krlevski

SPOTLIGHT 5

COMMUNITY SERVICES FOR PEOPLE WITH DISABILITIES IN ROMANIA - PENTRU VOI FOUNDATION

Objective of Pentru Voi Foundation Community Service

Pentru Voi is a non-governmental and non-profit organisation based in Timisoara. The goal of the work of the organisation is to increase the quality of life for persons with intellectual disabilities through the philosophy that Inclusion is built on the belief that all people are equal and should be respected and valued. Pentru Voi is providing their services partnership with the National Authority for Persons with Handicap and Timisoara City Hall. Users of the service are 100 adults with developmental disabilities and their families.

Main activities

The mission of Pentru Voi is to promote a new social policy based on UN Standard Rules on Equalization of Opportunities for Persons with Disabilities. The services provided by the organisation are:

- Day services; workshops, supported employment and Day Care centre
- Residential services; group homes and independent living homes,
- Community support; family counselling, social life and leisure activities, social accompaniment,
- Advocacy and self-advocacy; training of 80 self advocated and participation in national and international conferences and events.

Supported employment

The model of supported employment implemented by Pentru Voi has different components, but is mainly based on that job seekers have a 'job-coach' in order to manage to keep the job that they have been employed to. Over the region it has been shown that there are some possibilities for people with disabilities to obtain mainstream employment, but many people have huge difficulties to keep them for a longer period. A 'job-coach' would support the person through difficult periods and challenges faced during their work.

Pentru Voi has developed a comprehensive approach to support persons with intellectual disabilities to obtain mainstream employment. It involves the whole process from assessment of the job profile to vocational training, to make a job analyse to advocate the actual employer or company:

- Vocational profile and vocational trainings,
- Social skills training in order to prepare the person for the daily life during the employment,
- Job seeking and then job analyse,
- Matching of employer and employee,
- Advocacy,
- Support in the recruitment process,
- Job-coach depending on the individual needs.

Development of 'social enterprise' to sustain the residential service

Pentru Voi has developed a so-called Social Enterprise within their residential service component. The residential home DINU in the village Sacalaz, where 10 youngsters live together, has started a bakery in partnership with the Social Canteen in Timisoara. Since 2003 they are providing bread on a daily basis to through this partnership as well as to the local population in the village. In 2004, a training and assessment regarding the development of this bakery as a social enterprise has been initiated in collaboration with NESsT in Budapest (Non-profit Enterprise and Self-sustainability Team) and supported financially by Open Society. The profit from this bakery will be used to sustain the residential home for youngsters with intellectual disabilities.

Success factors for Pentru Voi Foundation to sustain their services

- Involvement of parents in the leadership of the foundation leading to increased motivation,
- Permanent support from foreign NGOs and DPOs (Inclusion Europe and Inclusion International),
- Partnership with the Town Hall of Timisoara,
- The permanent cooperation with NAPH (National Authority for Persons with Handicap), the EU Delegation and other international bodies,
- Permanent lobby activities,
- Strong motivation of leadership and staff.

7. MOVING AWAY FROM RESIDENTIAL INSTITUTIONS: DEVELOPMENT OF COMMUNITY RESIDENTIAL CARE AND ALTERNATIVE HOUSING

UN Standard Rule 9. Family Life and Personal Integrity (extracts)

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

- Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effect on family life.

The negative impact on the quality of life and increased cost of taking an individual out of the family or society is higher per client, than inclusive approaches to servicing vulnerable persons within their families and communities⁶¹.

7.1 Legacy and current context

Moving from the legacy of a social welfare system that relied extensively on a segregated and protective system of supporting families of children with disabilities, and adults with disabilities, to a system promoting rights and inclusion, is of course complex. An important objective is the transformation of the system of social and medical residential institutional care that was extensively developed throughout Eastern Europe. According to the World Bank's Tobis report, 1.3 million people live in 7,400 highly

structured institutions⁶². The report comprehensively details the state of residential institutional care in the region, focusing on Central and Eastern Europe. It gives recommendations switching to a system of Community-based social care for people with disabilities from one of institutional care.

Deterioration of living conditions in residential institutions

Economic decline and the transition to a market economy have caused severe deterioration of living conditions in many residential social institutions and homes. Although humanitarian support has been provided and certain training programmes have been implemented, the overall situation is worse today than a decade ago and several reports from international Human Rights organisations confirm this⁶³. In fact, the

BOX 18

Staff structure in residential institutions in Serbia

Activities linked to social work for people with mental disabilities and illness, (the variations are linked with the level of impairment: mild, moderate, and severe):

- One social worker for 150 persons,
- One lawyer for 150 persons,
- One defectologist for 50-100 persons,
- One occupational therapist for 100-150 persons,
- One vocational trainer in case there is a sheltered workshop,
- One manager.

Activities linked to general work of care, feeding and hygiene of the people with mental disabilities and illness:

- One caregiver for 6-25 persons,
- One chief cook for 300 persons,
- One waiter/waitress for 150 persons in the morning - 250 in the afternoon,
- One linen keeper for 50 persons,
- One tailor by institution - 2 if there are more than 500 persons,
- One hairdresser for 150 persons,
- One cleaning woman for 30 persons.

⁶¹ World Bank, "Romania Child Welfare Reform project: Human Development sector," project appraisal document, Europe and Central Asia Regional Office, (Washington, D.C.: World Bank, 1998).

⁶² David Tobis, "Moving from Residential Institutions to Community- Based Social Services in Central and Eastern Europe and the Former Soviet Union" (Washington D.C.: World Bank, 2000).

⁶³ Tobis, *ibid*, 26; Mental Disability Rights International (MDRI), "Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo" (Washington, D.C.: MDRI, 2002): 7-16; Amnesty International, "Bulgaria - Far from the eyes of society Systematic discrimination against people with mental disabilities" (October 2002): AI Index: EUR 15/005/2002.

support of the international community to residential institutions in terms of rehabilitation, food supply, clothing and other medical equipment may have had little positive effect. On the one hand, conditions for certain beneficiaries have improved, but on the other it has given a false impression to governments that institutional care is not so harmful if provided under favourable conditions. This goes against decades of research and evidence on the negative impact of institutional care, and has delayed the switch to a more cost-efficient and quality based care in the community, as has already happened in Western Europe⁶⁴.

Residential institutions, together with psychiatric hospitals that were developed within the previous system illustrate the concept of 'total institution' and all its characteristics as described earlier in the report. The work of professionals in institutions is often disconnected from the needs of beneficiaries, "the existing rulebooks do not recognise the needs of the users themselves as the starting point for setting the number and type of professional workers⁶⁵". As described in Box 18 the ratio of staff to clients was calculated based on the number of clients only and not on actual needs and standards relating to quality of life⁶⁶.

Children with disabilities in institutional care

The right to grow and be cared for within a family is ensured within the UN Convention on the Rights of the Child especially mentioned in article 5, 10 and 18, and is equal for all children, with or without disabilities. In the former system, families with children with disabilities did not have the appropriate support to care for their child within the family environment and when they did express their concerns, they were often persuaded by doctors that a public institution would be better for the upbringing of their child. This resulted in an over-institutionalisation of children with severe disabilities, mainly children with intellectual or multiple disabilities. Foster families, respite care services or counselling centres were poorly developed within the social protection network for children with disabilities and the reliance on the state as the substitute caretaker for children without parental care and children with disabilities was the main solution⁶⁷.

7.2 Initiatives for change

As described earlier, the international community pushed the initiation of de-institutionalisation in the region when communism collapsed and the situation in residential institutions was exposed. Several new NGOs were formed with this external support and they became the main stakeholders in the process of transforming institutional care and the development of alternative services at community level in particular. Often community level services were developed in parallel to the state welfare system, with quality standards far ahead of existing ones (where they existed) and with staff salaries much higher than in public welfare institutions. This has resulted in a range of new services, set to support a transformation of the residential care system. However, a lack of understanding between the states and professionals working in institutions, and the NGO community is slowing the process. As discussed later in the final chapter of the report though, there are several initiatives for collaboration between state and civil society initiated.

De-institutionalisation of mental health services

In the UN administered province of Kosovo, reform of mental health services was implemented following heavy criticism of the main institute for psychiatric services in Shtimje⁶⁸. The Ministry of Health initiated a 10-year Community-Based Mental Health strategy with the support of the WHO. The aim was the transformation of Shtimje institute into an open institution. Parallel to this, ten community mental health centres will be established to provide services within the community. Connected to these centres there is a programme to develop apartments for up to 10 people, to facilitate their reintegration into the community. At the moment this project is in the early stages, and the crucial point will be the training of staff to adopt the social approach to disability. This is crucial, in order to ensure that these centres and apartments are not another form, albeit more friendly and humane, of social exclusion. The WHO has supported similar reforms in Macedonia and Albania over the last 2 to 3 years.

UN Convention on the Rights of the Child (extract)

Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community.

⁶⁴ Tobis, *ibid*, 25-26

⁶⁵ Vesna Bosnjak et al., "Institutions and Services," report for the Ministry of Social Affairs, Serbia on transformation of residential institutions, 17.

⁶⁶ Information comes from the Law on social protection and social security sub-legal act on residential institutions - 1993, Serbia.

⁶⁷ Tobis, *ibid*, 7-10.

⁶⁸ Mental Disability Rights International (MDRI), *ibid*, 4.

BOX 19

The Association for Promoting Inclusion's programme of Independent Living homes in Zagreb, Croatia

The Association for Promoting Inclusion (API) is working in partnership with the Centre of Social work on this programme. The aim is to re-integrate person with intellectual disabilities currently in residential care, into the community. The process of the re-integration follows the following methodology, developed after several years of experience and users' feedback:

API team members together with professionals of the institution in question identified people who were willing to attempt this change process and way of living. Clients may choose their preferred type of housing. Each house or apartment houses one to five clients. Caregivers, employed for a trial period of 3 months are identified, trained and closely supervised, and if both parties are satisfied a contract is signed. A support team within API, consisting of a special educator, psychologist, social worker and nurse designs the individual support plan together with the client. The team also helps the clients and caretakers to implement the plans, creating a social network.

The key steps of the API programme Homes for Independent living are:

- Community-based housing in apartments in accordance with the choices of clients (1-5 persons share an apartment) with the degree of needed support provided,
- Providing assistance and improving the competence of clients in day-to-day activities and situations (handling money responsibly, keeping the apartment tidy, taking care of their clothes and laundry, acquiring and preparing food, taking care of their appearance and their health, use of the public transportation system, development of positive relationships among the Clients sharing the same apartment,
- Increasing the level of competence of the clients by enabling them to take part in the life of the local community (building a circle of support, involvement in work, cultural, recreational, sport or religious activities offered by the local community, inclusion in work activities in the private and state sector).

Results of the programme

81 adults with intellectual disability living in residential institutions have been re-integrated into their communities and are living in rented apartments that form the 'Homes for Independent Living'. In Zagreb, there are 50 clients in 22 apartments, 27 clients live in 7 apartments in Osijek and 4 clients share an apartment in Bjelovar. A strong lobbying and advocacy process was directed towards the Ministry of Work and Social Welfare in order to ensure the programme was included as an alternative in the Social Welfare system, and that it was financially sustainable. In April 2000 the Ministry for Social Welfare recognised the first 'Home for Independent Living' in Croatia as an official alternative to residential institutions.

Lobbying toward the Ministry of Labour and Social Welfare for recognition

API's strategy for the recognition of this project was to propose that the funding provided to residential institutions followed the client to the new residential facility. This means that after the Centre for Social Work approves the de-institutionalisation of the client, the API Home for Independent Living signs a contract with the Ministry of Work and Social Welfare that covers the living expenses of the client. These are expenses related to rent, support from the expert team, living costs of clients and their per diem etc which is equal to approximately 720 EUR per person per month, a saving of 200 EUR per month on the cost of state residential institutions. API still has some additional costs since this fee does not fully cover the expenses for the clients in the apartments. The most important criteria from the Ministry in the negotiation process seem to be that this type of community based housing programme should be less expensive than traditional residential institutions.

Average staff ratio

- 1 special educator for 20 clients
- 3 caretakers for 20 clients (may depend on the need of the clients)
- Psychologist, social worker and nurse during team meetings once/month

Re-integration in the community through Independent Living homes in Croatia

An interesting experience in improving social participation and living conditions for persons with disabilities is a project named "Homes for Independent Living", a partnership between the **Association for Promoting Inclusion (API)** and the **Centre for Social Work in Zagreb** (Box 19). The aim is to re-integrate people with intellectual disabilities currently in institutional care, into the community. The project started in 1999 and the methodology for re-integration has been refined through experience gained whilst implementing the project and with the help of user feedback. To date, 81 adults with intellectual disabilities have been re-integrated into their communities in three municipalities in Croatia, and the program is as well today part of the alternative residential care within the social protection scheme.

Transformation of residential medical institution in Albania

As discussed at the beginning of this section, the development of services within the community provides an opportunity to transform the existing system of residential care. The goal is to close all large residential homes, and only provide institutional care as the last resort of support, and in such a case in family like homes close to the origin community of the child.

Following the collapse of the communist system in Albania, the **National Centre for Growth and Development Rehabilitation** was undergoing a major change within the general process of transforming this traditional residential institution into a referral and resource centre with a community based approach. This centre has also developed a resource and training programme, where staffs of several Family Medical Centres throughout the country have received training in early detection and intervention, as well as screening tools for children showing signs of developmental difficulties. In the spotlight at the end of this chapter, a presentation of this successful transition is provided as well as a detailed description of the current activities.

Day Care centres supporting the de-institutionalisation process

In Macedonia, a program of de-institutionalisation was initiated in partnership between UNICEF and the Institute of Defectology within one of the bigger residential institutions for children and adults with intellectual disabilities in Macedonia, Demir Kapia. Twenty children have so far been re-integrated in the community, either with their natural families, or in foster families. In the communities where these children were re-integrated, a system of Day Care centres was established as well in order to support the "new" families in this process. So far five Day Care centres have been established, offering daily services to children with intellectual disabilities.

Another initiative for establishing Day Care centres in Macedonia has been implemented by the **Republic Centre for Support of Persons with Intellectual Disabilities (Message/PORAKA)**⁶⁹. Four Day Care centres were established to achieve their objective of supporting the de-institutionalisation and inclusion of people with intellectual disabilities into society. The Day Care centres are mainly financed by the National association, but managed at local level by the branch organisation. PORAKA is lobbying the Ministry of Labour and Social Policy for financial support and the recognition of Day Care centres as an alternative social service for people with intellectual disabilities. In total, these four centres provide services to 80 children, adolescents and adults with disabilities.

From isolation and indifference to family and identity - foster families for children with disabilities

Foster family services have not been very much developed in the countries of South East Europe (except Croatia), and certainly not for children with disabilities. Strong prejudice and the medical approach to disability have hindered this development. Over the last few years however, some initiatives have been tried, and their experiences show that it is possible to create service of foster families as well for children with disabilities according to similar concepts as regular foster care, but with additional training as well as some additional support within the community for the families. Below are presented two experiences, one from **Motivation** in Romania and one from **Association for Promoting Inclusion (API)** in Croatia (Box 20).

The main condition for success for both programs seems to be the work on raising awareness in the communities where the children will be placed. Prejudices and fear are still the main reasons why families are reluctant to include a child with disability in their environment. Other factors for success are the actual existence of supportive services within the close community where the children are placed and the financial support given to the family. Once these conditions have been met, even if only the first two, families are often ready to consider adopting the child they took into foster care.

It is also important to have a well-planned and professional training program, to prepare both the child, based on its individual abilities and needs and the future foster parents. In cases where the assessment and matching of the child with the foster parents was done hastily and the initial feeling of the child was not positive, the integration of the child failed. It shows that this is a delicate process, that both the child and the parents must be prepared and that it is crucial to take the wishes of the child seriously. These two projects show that it is possible to offer foster family service or family like group homes for children with disabilities and that the process of preparation and integration is similar to that of other foster services.

⁶⁹ Information gathered during an interview with Dr. Vasilka Dimovska president of PORAKA in Skopje, 2004.

BOX 20

Foster family for children with disabilities in Romania and Croatia

Motivation Romania Foundation is an NGO, active since 1995 in providing various services for people with disabilities. Their core mandate is to work with persons who find themselves in a situation of disability after a spinal cord injury. In partnership with three other local NGOs and the IMPACT alliance they started a programme of *"In-family care of children with disabilities and the continued development of community alternatives to the institutionalisation of disabled children"*. Motivation's role is to run a project to re-integrate children with disabilities from residential children's homes back into the community, either through foster families, or within 'family group homes'. The project started in 2002 for 22 children residing in one social institution within the Ilfov County, aiming to re-integrate them into their biological family or to identify foster families. It implied the following process:

1. Construction of 3 small housing units for the transition period before the children are placed with foster family or natural family, and possibly for long-term stay for a certain number of children where foster families cannot be found,
2. Training of staff within these units,
3. Preparation of the child for the new placement in terms of re-nourishing, daily life skills, social behaviour training etc,
4. Identification of foster or natural family,
5. Training of the foster or natural family (disability awareness, making the house accessible, identification of network around the family,
6. Support to the families after the re-integration,
7. Advocate and lobby for these services to be part of the social protection at the County level preferably through a subcontracting process of NGO as service providers.

External donors fund this project so far, but an agreement has been reached where the social welfare payment for residential care is partly transferred to the foster families or family group homes (\$150 for families and \$40 for children remaining in group homes). This amount is far from sufficient to cover basic expenses and additional costs for transport, technical aids or diapers that most families will need.

The second successful initiative in the development of foster services for children with intellectual disabilities stems from the experience of the **Association of Promoting Inclusion** in Croatia. API developed their programme of specialised foster family care for children with intellectual disabilities in the course of their de-institutionalisation efforts. The process of this service implemented in collaboration with the Centre for Social Work, developed after 7 years of experience is as follows:

1. Advertisement for possible foster family (if natural family cannot be found or is not a suitable solution) in media and television,
2. Initial meetings and assessment of the interested family with the social worker and special educator of the API Foster Care support team,
3. First meeting with the child and the foster family, followed by 4-5 weekend meetings,
4. If the child and the family find a 'mutual love', the Centre approves the process of placement for Social Work, who is the responsible institution for placement of children without parental care. Foster families that care for a child with a disability have an allowance which is 20% higher than the allowance for fostering a child without disabilities (total 200-250 EUR/month),
5. API provides training to the foster family prior to the final placement - individually and in groups,
6. Together with the child and the foster family the professional support team of API designs an individual support plan for every child,
7. A special educator is assigned as the coordinator for the child and is responsible for coordinating the implementation of the individual support plan (one coordinator is responsible for 20 children),
8. API provides support to the foster family and the child on a weekly basis in order to ensure the integration, and then monthly support is provided if needed (by a team of psychologist, social worker and special educator),
9. API tries to find additional financial support to the foster families with a system of "god father support", often business men or international companies,
10. Once the child turns 18, the opportunity of the earlier described Independent Living Homes is available also for these young adults.

7.3 Looking ahead

Several recent reports by human rights organisations, UNICEF and Save the Children indicate that the situation in residential institutional care has not improved much over the last decade⁷⁰. Economic and social deterioration has indeed worsened the living conditions in residential institutions, approaching, and some times exceeding, the limits for violation of human rights.

Taking the good practices described, for example the program of API in Croatia, where the Independent Living homes have become one alternative for supported living apart from residential institutional care, it has been demonstrated that it is not more expensive to provide this individualised type of support whilst ensuring the principles of UN Standard Rules of integrity and possibility for family life.

Main priorities in the close future to ensure the right to participation and inclusion and to transform the system of residential institutionalised care are:

- **To continue to develop supportive services at community level, in order to ensure a chain of needed services,**
- **To the widest extent mainstream ordinary services, but as well provide specialised services for supported living and personal assistance,**
- **To connect these types of services with inclusive education and mainstreaming of employment in order to ensure that services developed do not end up to be another form of exclusive specialised services for persons with disabilities,**
- **Transformation of the existing system of residential institutions into smaller family like units, or resource structures for special education, counselling centres or respite care structures.**

Decreased reliance on institutional residential care can be facilitated by a comprehensive social protection system, offering various forms of support (i.e. financial, technical and psychological) to the family from the onset of the disability, combined with an inclusive approach to education and employment.

THE NEED TO DEFINE COHERENT STRATEGIES FOR THE DEVELOPMENT OF AN ENABLING SYSTEM

The analysis of the systems of services for people with disabilities in South East European countries shows the picture of a system in transition, where the legacy of the old system still causes resistance to the emergence of a community-based and inclusive system of services. Many services being developed are still exclusively for people with disabilities and developed by professionals without involvement of users or their representatives (DPOs). Even though a process of change towards a more enabling system has been initiated, this de-institutionalisation process remains unsteady and uneven, being rather the sum of isolated initiatives than the coordinated implementation of a comprehensive and coherent

strategy. Many of those initiatives are facing difficulties reaching sustainability.

Nevertheless, such good practices demonstrate the feasibility of community-based and inclusive services in the region, and contribute to sensitisation of professionals, users and decision makers to holistic approaches to disability. To build an enabling system, beyond sustaining the existing initiatives and disseminating new services, there is a need to develop and implement coherent national strategies, based on the holistic disability paradigm. This should be a shared responsibility among various stakeholders.

⁷⁰ UNICEF, *Generation in Jeopardy: Children in Central and Eastern Europe and the Former Soviet Union* (New York: M.E. Sharpe, 1999); Andy Bilson and Ragnar Gotestam, "Improving standards of child protection services - a concept paper" UNICEF Innocenti Centre (Florence: UNICEF and World Bank, 2003); Amnesty International, "Bulgaria - Far from the eyes of society: Systematic discrimination against people with mental disabilities."

SPOTLIGHT 6

TRANSFORMATION OF RESIDENTIAL CARE IN ALBANIA

National Centre for Growth Development and Rehabilitation Tirana (NCGDR), Albania

In 1998, this institution, which was then a Social residential Institution for children suffering from malnutrition, was approached by Caritas Switzerland who wished to support the development of the centre that was in very poor condition. The centre accommodated around 100 children at the time. Caritas support was conditional on the institution being transformed from a closed to an open one. A working group of experts was created and Mrs Donika Naqi, from the Ministry of Health, already working part time in the institution became a driving factor for the implementation of this strategy. This expert group, strongly supported by the Ministry of Health, worked out a plan for transforming the institution into a referral and resource centre for children with developmental disabilities. Mrs. Naqi became the head of this project.

Process of transformation

In 2000, a re-organisation of the staff was initiated, with a reduced number of medical doctors and replaced by an increased number of psychologists, social workers, physiotherapists and pedagogues (and later on occupational therapists trained abroad). Simultaneously, a process of re-integrating children residing in the centre into their natural families, foster families or other alternative accommodation for children staying in institutions was instigated. By 2001, the centre had completed its "transformation" and only 6 children where a family could not be found remained in the centre. The centre was then renamed the National Centre for Growth Development and Rehabilitation for children 0-6 years old with developmental difficulties and intellectual disabilities.

Activities today

- 30 beds for children newly diagnosed with developmental difficulties, according to a "rooming-in model" where the parents stay with their child while receiving training and information about the development of their child over 1-3 weeks,
- Kindergarten for children with disabilities where children in the surrounding community are welcome and the children who attend the centre with their parents can benefit as well. Activities provided are daily life skills, educational activities, speech therapy, physiotherapy and social activities according to the individual needs of the children,
- Counselling and support to parents in the afternoon,
- Home visits to children with disabilities in the surrounding community by social worker and pedagogue,
- Training courses for Primary health care centres (mainly doctors and nurses) around Albania on early intervention and detection of disabilities, introduction of screening tests and evaluation forms,
- Development of manuals and information for parents in collaboration with Medical University.

Key steps in the transformation process

The transformation of this residential institution into an open public institution serving as a referral and resource structure in the field of developmental difficulties among children 0-6 years is an interesting experience for the region. Key areas of success are:

- The support of the Ministry of Health,
- The intensive work and dedication of certain individuals (such as Mrs Naqi),
- The conditional financial and technical support for change by international stakeholders,
- The success of integrating and finding alternative residential facilities for children accommodated in the institution,
- The training of the professional staff, as well as the replacement of certain categories of staff, supported by international agencies and professionals.

Sustainability

Financially the NCGDR is sustainable but as in all other public institutions, salaries are at a very low level, and in order to keep motivation and dedication high, management tries to support the staff financially by providing training to other structures, by providing continuous training abroad or by bringing experts to Albania. Consequently, all community based activities, as well as training activities are funded via external donors and thus far the Ministry of Health does not intend to take over this financial responsibility.



PART III

ACHIEVING THE CHANGE: KEY STEPS AND SHARED RESPONSIBILITIES



MOS NA
IZOLONI

PART III

ACHIEVING THE CHANGE: KEY STEPS AND SHARED RESPONSIBILITIES

As presented in the last section, various types of services based within the local community are emerging throughout South East Europe, moving towards more inclusive service provision for people with disabilities. However, the initiatives are not part of a coherent reform strategy at the state level.

Because the emergence of an enabling system is occurring within the context of an economic and political transition, resources are limited and state and local actors are redefining their roles and responsibilities. There is a high risk in the region that the states will withdraw their funding from what was a very protective care system without developing proper alternatives and long-term strategies for an enabling system for people with disabilities.

However, the emergence of **an enabling system** is not simply a matter of creating a safety net that would protect people with disabilities from extreme poverty, **it is about an investment which if made during the transition, will facilitate the equalisation of opportunities and full participation of people with disabilities.** In order to move beyond the de-institutionalisation of care systems towards an enabling system, a change in the overall disability paradigm is needed. The holistic model and a human rights-based approach have to become the norm for perceiving disability.

Within the region, EU accession, poverty reduction strategies and decentralisation processes offer unique opportunities to mainstream disability and develop a powerful global alternative to institutionalisation in a cost effective manner. Therefore, the necessary changes in the approach to disability call for widespread mobilisation of local stakeholders such as states and civil society, who all play a vital role on a local, national and regional level ensuring that the transition to an enabling system should accompany the decentralisation process. To ensure an effective implementation, all the reforms impacting disability need to be placed in a National Disability Strategy. These strategies should be comprehensive and cross-

cutting, and involve people with disabilities and their representatives in the planning and implementation processes.

The twin track approach

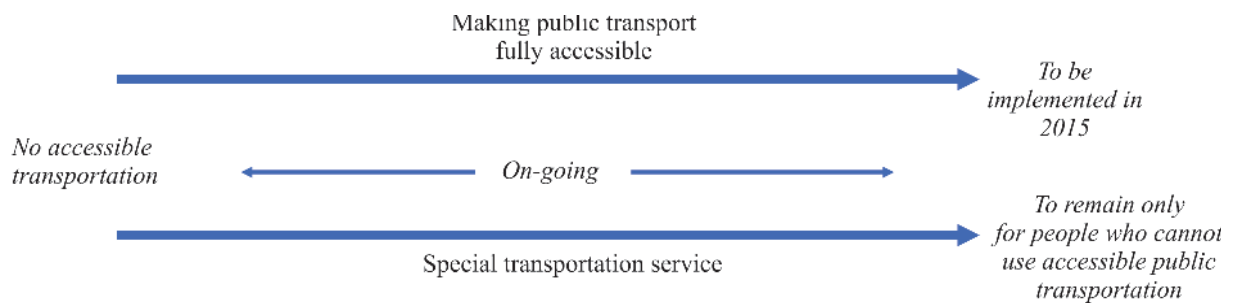
Building an enabling system is a long-term and resource consuming process. Achieving equal opportunities to participate in all sectors of society for people with disabilities will require many systemic changes. Meanwhile, people with disabilities are among those who suffer the most from the dismantling of the state social welfare systems, and they experience discrimination daily and social exclusion. Therefore, states should adopt a **twin track approach** as a way of operating the change process towards an enabling system, so that during the transition, action is taken to meet the needs of people with disabilities and promote immediate changes. While everything should be done to create an enabling society, affirmative action, special services and anti-discrimination legislation are still required to address the specific problems that people with disabilities face on a daily basis. It is a two-pronged strategy consisting of direct intervention with people with disabilities along with inclusion of disability in overall policy-making⁷¹.

Mainstreaming

The objective of mainstreaming disability is to enable people with disabilities to integrate into key areas of society such as education, health, social protection and employment. Mainstreaming must be part of the state's reform agenda so that disability issues are mainstreamed into all levels of policy planning.

In the earlier stages of the change process, it requires state action to create specific disability mainstreaming programmes in order to force a change in the environment. Meanwhile, mainstreaming will need to be implemented progressively through a change in the perception of disability, proper training of professionals in regular services and the redirection of resources to create incentives for inclusion.

⁷¹ Inclusion of disability in Dutch Development Co-operation Policy and Practice (November, 2003): available at <http://www.dccd.nl/default.asp?action=article&id=1830>

Scheme 5. Twin track approach: example of transportation**Special programmes and services**

However, the twin track approach acknowledges the long-term nature of transformation. Therefore, in the planning process, specific services will be built to answer to some specific needs of people with disabilities so that they can have a sustainable livelihood in dignity during and after the transition. Even in a supportive and barrier free environment, some people with very severe disabilities will always need some specific support in terms of medical assistance, rehabilitation and education.

For example, as shown in scheme 5, in the process of making transportation fully accessible, the state will provide special adapted transportation for the period of transition. This way, the system provides people with disabilities services to meet part of their needs until all transportation is made accessible on a universal level. Then demand for special transportation services will decrease and remain mainly for people with disabilities that cannot use the regular and newly accessible public transportation. Moreover, one of the most important of the specific considerations to people with disabilities is the support to self-representation and thus to organisations of people with disabilities.

Towards an enabling system

Examining the current dominant paradigm for disability and ways in which this model can be shifted towards inclusion and participation through policies and care system governance is important, particularly during this period of transition and transformation in the region. As the World Bank and EU introduce reform mandates

and new values, it is particularly important to clarify how the model for disability should be shaped by the state in collaboration with civil society in order to truly build an enabling system based on full participation. This next section will explore how the governance of an enabling system should be underpinned by the values of social rights, political rights and self-determination. Services and social welfare should be structured around quality and choice in which the client is proactive, a kind of 'performance' governance in which service provision is measured by effectiveness in reaching individual needs⁷². In addition, legal changes combating discrimination and removing barriers are needed to accompany the emergence of an enabling system. Some critical steps must be taken in order to achieve this move:

- Acknowledgement that the change process is a shared responsibility between all stakeholders in the region including the state, local civil society and the international community,
- Changing perceptions of disability among the population, starting with people with disabilities themselves, their families and professionals,
- The implementation of comprehensive and anti-discrimination legislation initiating long term change and promoting equalisation of opportunities,
- Redirecting resources to community-based services and reforming gate-keeping mechanisms,
- The development and implementation of a National Disability Strategy that encompasses all reforms that impact the lives of people with disabilities and the empowerment of a National Council on Disability.

⁷² Kathryn Ellis, Human Rights, professional practice and social care: the findings of a small scale research study," in Disability Studies: From Theory to Practice (Lancaster: Lancaster University, July 2004): 4-6.

1. THE VARIOUS STAKEHOLDERS IN THE TRANSITION

1.1 The state

States in South East Europe are all facing similar challenges in the move towards an enabling system for people with disabilities:

- A painful transition severely limiting the states' resources,
- A growing number of vulnerable populations not covered by the social welfare system, including people with disabilities,
- The need to reform the care system,
- The lack of comprehensive strategies for disability

The main obstacles facing states in South East Europe in the move towards an enabling system come from the major constraints imposed on them by transition and post-conflict development, limiting their capacity to make reforms. However, because of the collapse of the former socialist social welfare net and due to internal and external pressure to change the care system, states in the region are compelled to act on many different fronts simultaneously⁷³. In the case of most countries in South East Europe, there is heavy pressure from external donors and development agencies to reform the social welfare system and social protection. At the same time, there is strong internal pressure to reduce the number of emerging risks forcing states to consider social reforms.

For most of the countries in the region, the systems are highly centralised but without the financial resources to maintain these frameworks. Decentralisation is underway but has not yet become effective in terms of a redistribution of financial resources. Post-Dayton Bosnia and Herzegovina is an example where decentralisation has been implemented administratively but is lacking the financial resources to respond to local needs. According to decentralisation directives in place throughout the region, many responsibilities for social and health services provision and financing have been transferred to local authorities. However due to the absence of a concomitant care system reform strategy and to the lack of resources, states are often unable to meet their citizens' basic social and medical needs.

States in the region have begun to initiate partial reforms that are more in line with the new disability paradigm. In Macedonia, the government has adopted legislation to offer financial incentives to employers who hire people with disabilities along with funding to cover the cost of adapting the work environment. A national disability plan of action is currently being drafted in Albania in a participatory manner involving the government and local DPOs in an attempt to build a comprehensive strategy for disability (see 5.2). In Serbia, the Ministry of Labour, Employment and Social Affairs is supporting a social innovation programme to help fund the cost of the transition to alternative services (Box 21).

BOX 21

Social Innovation Fund Serbia

The strategy behind the Social Innovation Fund (SIF) is that it acts as a sustainable strategy to interface between government and other actors such as NGOs, donors, private sector as well as public institutions in the reform of social welfare. SIF's contribution to the change process focuses on the following priorities:

1. To emphasise the participation of beneficiaries in the design and provision of social services,
2. To address needs of individuals within the context of family and community,
3. To maximise community-based services over institutional services (as part of the process of de-institutionalisation of social care services),
4. To offer service diversity and choices to beneficiaries and,
5. To encourage plurality of service providers.

At the same time, it sets a framework for investment in alternative forms of social services therefore contributing to reform in the social welfare sector. SIF is designed to create mechanisms of 1) decentralisation by financing pilot projects at the local level, 2) transition by helping the local community to develop and finance services therefore, covering the costs of transition 3) capitalisation on good practices and lessons learned and 4) alleviating marginalisation by making care system services accessible, affordable and user-oriented contributing to inclusion and empowerment for vulnerable populations.

SIF was designed to be a transitory mechanism during the reform process so that it would fund the change from centralised to decentralised social services. SIF is also designed to act as a body coordinating reform initiatives between the local level and the central government level.

Source: Rising Standards, Access and Self-reliance, Ministry of Social Affairs report, 2003

⁷³ Vesna Bošnjak, "Social services-The Heart of Social Protection Reform: Lessons from Serbia" Report for UNICEF Belgrade (Belgrade, 2004): 2-3.

The structure of the state, centralised versus a decentralised type of government and their approach to the transition influence how and when reforms can be implemented.

The structure of the state and the reform

The impact of a centralised system on the reforms:

- When promoted by the state, legal aspects of reforms will take place rapidly proposing a universal transformation of the system,
- If there is resistance to reform at the central government level, these changes will be blocked or will move at a very slow pace,
- Change in government administration can dramatically impact the momentum of reform.

The impact of a decentralised system on the reforms:

- With a proper allocation of resources, a decentralised system has mechanisms in place for the actual implementation of reforms at the local level,
- A decentralised system has the capability of taking a more practical approach to reform such as launching pilot projects on the local level, devolving ownership to various local NGOs, DPOs and community organisations,
- When the reform is not harmonised throughout the various administrative level and entities, it leads to discrepancies in how initiatives and legislative reforms are implemented preventing universal reform. This could lead to dramatic inequality of rights and types of services people with disabilities have access to depending on the different area in which they live such as the case in Bosnia and Herzegovina.

Different approaches to reform

There are generally two approaches a country can take when initiating reform of the care system; first reform the legislative framework or begin the change process with pilot projects changing the system through experience. The optimal situation is a combined approach where legal changes accompany systemic ones such as inclusive policies for people with disabilities or changes in services using the holistic approach.

Reform of the legislative framework

One way states in the region can initiate the shift towards an enabling system is by implementing widespread legal reforms with the objective of enabling people with disabilities to participate fully in society and enjoy equal opportunities. These legal reforms include:

- Anti-discrimination legislation,
- Comprehensive legal frameworks promoting equal opportunities through an adequate incentive income maintenance system, inclusive legislation on education and employment,
- Laws on accessibility to the built environment and communication such as universal design

Traditionally in the region, stakeholders relied on legal

frameworks as the catalysts for change. Changes in the law seem to be the first step taken to initiate reform and many advocacy groups consider legal reform as a unique target. Field observation shows that new laws, while they may be good in theory, are rarely enforced due to a lack of policy implementation, resources and training of the professionals involved. Improvements of legal frameworks can become powerful tools to initiate reforms and heighten awareness of disability issues but only if accompanied by strong enforcement mechanisms and strategies to make the changes happen in practice (this is expanded upon in chapter 3.1).

Reform based on experience and pilot projects

States can move towards an enabling system by first initiating the changes in existing practices through training of public service professionals on the holistic approach to disability, and reforming the assessment of needs of persons with disabilities within Centres for Social Work. The best way to change care system practices is through pilot projects so that the state can learn through experience and capitalise on lessons learned. In Serbia, the Social Innovation Fund (SIF) was established as a mechanism to fund, via tender, local pilot projects that take a new approach to social service reform. The SIF is co-sponsored by the Ministry of Labour, Employment and Social Affairs Serbia, the UNDP Belgrade and the Government of Norway (Box 22).

There are many advantages to using the pilot project method for reform according to David Tobis, foremost scholar on the de-institutionalisation movement in Eastern Europe and the former Soviet Union. Using pilot projects to transform the care system allows for:

- Flexibility to develop a wide range of approaches to reform,
- Opportunities to develop correct approaches learning from mistakes on a small scale,
- Data collection,
- The opportunity to initiate policy dialogue and eventually a shift in the paradigm for care and social protection⁷⁴.

One of the critical issues of the pilot-project approach is the phase of replication or scaling up when successful projects are proliferated on a larger scale. The resources, financial, political or professional, used in pilot projects are rarely assessed substantially in order to establish relevant parameters that will make the replication of the best practices realistic. As a consequence, when the lessons learned from pilot phases are used as a base for legislative change, for instance, the lack of clear knowledge on the cost of such a reform could become an obstacle in the change process.

The two manners of reform are not mutually exclusive. Having a legal framework to support equal opportunities and accessibility is critical for making immediate changes in the environment. However

⁷⁴ Tobis, *ibid*, 51.

legal changes are not enough. Changes in legislation need to be accompanied by changes in practice such as mainstreaming programmes, re-training of professionals, and new quality standards, changes that take a longer time and more resources to implement.

1.2 Local civil society

The main challenges facing local civil society in the transition towards an enabling system include:

- Civil society is lacking experience in social reform and alternative service provision,
- Civil society does not yet consider disability as a cross-cutting issue (as is the case for gender),
- The issue of disability has not been mainstreamed into the reform agenda by civil society.

Civil society in South East Europe is in its infancy and just beginning to develop. It is lacking the experience in social reform that civil society actors in Western Europe have had time to gain. Under the former regimes, civil society was organised by the state and therefore did not develop a significant spirit of social innovation. However, as the transition process in South East Europe develops, a large fleet of civil society actors have been mobilised mainly due to the prevalence of international agencies arriving in the region in the 1990's and the stream of economic assistance from external donors to fund the development of civil society. Unfortunately, this dynamic has had very little effect on organisations of people with disabilities. Civil society in South East Europe as a whole does little to address the issue of disability.

It is a critical stake in the change process for civil society in South East Europe to be mobilised around the new disability paradigm, mainstreaming disability into their agendas so that trade unions and human rights organisations view disability as a part of social and political reform. The issue of disability needs to be mainstreamed into civil society's agenda so that not only DPOs are responsible for advocating for the development of an enabling system for people with disabilities, but also that they work in partnership with the wider civil society stakeholders on fostering the change.

Organisations of people with disabilities

Organisations of people with disabilities (DPOs) should be the leading stakeholders of civil society in lobbying for the rights of people with disabilities and for the provision of adequate services. They should also be consulted and have an advisory role in the development of national policies, services, and other decision making bodies at the national and local level. However, the main challenge in the region is the building of a unified voice respecting the diversity of the disability movement. This disability movement is currently characterised by:

- Conflicts and internal competitive behaviour between different DPOs undermining the capacity of the disability movement,
- Many DPOs focus on specific disability issues rather than a cross-disability agenda with a lack of effective coordination body,
- Many DPOs lack the capacity to build the disability movement and lobby effectively.

Under former Yugoslavia's previous system (and still in use today in successor states), DPOs were organised in a pyramidal structure of unions, each representing a specific category of disability. These unions had branches at the local level, and it was almost automatic for a child or an adult with disabilities to register with the local branch of their nominated union. Membership gave certain benefits such as free public transport and certain types of care support. Some unions also managed workshops and printing companies for Braille books, magazines, etc. The state funded these unions based solely on the number of registered members, with no monitoring of activities. A recent UNICEF report qualified this system as "outdated associations according to the nature of disability. Most of these organisations focused on obtaining benefits and entitlements for their members and paid little attention to their rights⁷⁵". Very few organisations of people with disabilities existed in Albania and Romania during the communist era, since civil society was extremely controlled, supervised and sheltered at the state level.

The member associations of the Unions have had difficulties in adapting to the new situation. They

UN Standard Rule 18. Organizations of Persons with Disabilities (extracts)

States should recognise the right of the organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisation of persons with disabilities in decision-making on disability matters.

- States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates,
- States should establish ongoing communication with organizations of persons with disabilities and ensure their participation in the development of government policies,
- The role of organizations of persons with disabilities could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, and to contribute to public awareness and to advocate change.

⁷⁵ UNICEF, A Brave New Generation, ibid, 39.

BOX 22**Self Help and Advocacy for Rights and Equal opportunities South East Europe (Share-SEE) www.share-see.org**

The Share-SEE initiative is a project that enhances the disability movement in the region: It is a regional cross-border project that is implemented in a partnership between DPOs and international organisations. The DPOs involved in this project are cross-disability oriented, with an independent living approach and involved in advocacy work. Relying on the empowerment of DPOs, Share-SEE expects to support changes in the attitude of the community, society and public authorities in order to create an environment where people with disabilities have equal opportunities. The different organisations involved in the implementation and management of the programme are:

Association of disabled students of Serbia and Montenegro (ADS-SCG): Established in 2000, ADS is a cross-disability DPO that aims to improve the integration and participation of young people and students with disabilities in society.

Centre for Independent Living Serbia (CIL Serbia): The mission of CIL is to promote the philosophy of Independent Living and create conditions for its implementation in Serbia. By campaigning and advocating, CIL has been actively working towards the realization of basic Human Rights of people with disabilities and improvement of their daily life.

Handicap International: International humanitarian organisation, Handicap International has been working in South East Europe since 1992. Handicap International's five-year strategy, 2004-2009, in the region focuses on support to key stakeholders involved in the change process towards the development of an enabling care system and inclusive society.

Information Centre Lotos (IC Lotos): Information Centre Lotos for people with disabilities is a DPO in Bosnia and Herzegovina active since 1997. IC Lotos aims to create a democratic civil society in which disability issues will be considered as human rights issues and people with disabilities will have no barrier to experience education, employment, livelihood and freedom of movement.

Union of Citizen - Polio plus - Movement against Disability (Polio Plus): Established in 1999, Polio plus is a Macedonian cross disability and multi ethnic DPO that focuses on self-advocacy and awareness rising on disability rights.

Regarding monitoring and evaluation as a well as capacity building, Share-SEE benefits from the methodological support of INTRAC (www.intrac.org).

The specific objectives of the project are:

- Organisational development of Disabled Peoples' Organisations,
- Development of a cross-disability, cross-border disability movement,
- Building a unified voice & constitution of an advocacy force,
- Campaigning for acknowledgement of rights of people with disabilities,
- Awareness raising amongst people with disabilities & within the community,
- Improvement of access to rehabilitation & health services,
- Initiatives to improve access to education & employment,
- Improvement and monitoring of the policies and reforms.

Regarding policies and legal frameworks the main objectives are:

- The development of a comprehensive national disability strategy (such as in Croatia) linked to the PRSP and EU accession processes,
- Enforcement of anti-discrimination acts and systematic law in all the countries,
- Enforcement of proper accessibility rules and regulations,
- Development of progressive social protection legal frameworks (personal assistance, reform of gate-keeping based on needs-assessment, public financing schemes for community services, and support for community-based care enhanced),
- Development of employment and education laws and policies promoting and enhancing inclusion.

endured the full impact of the fall of the communist system and lost part of their representation and funding as a result. However, as shown in part II, the Republican Centre for Support to Persons with Intellectual Disabilities in Macedonia, PORAKA (Message), is an example of how DPOs stemming from the previous system of unions can be progressive civil society actors adopting a more contemporary approach to reform opening Day Care centres and inclusion initiatives. This organisation has been involved in the monitoring of implementation of the UN Standard Rules with the support of Inclusion Europe⁷⁶.

As governments begin to retreat in the decentralisation process, civil society actors will take on a more significant role⁷⁷ in the move towards equal opportunities and full participation of people with disabilities. However, in order for this transformation to take place, the disability movement must be stronger so that it can advocate for critical changes. Therefore, there is a need to mobilise a grassroots constituency behind the disability movement with strong networking and partnership to facilitate the lobbying process.

Share-SEE is a regional programme aimed at fostering a unified voice amongst the various local civil society stakeholders and empowering DPOs to be capable of change (Box 22).

1.3 The international community

International actors such as the UN, the World Bank, the EU and International NGOs play a role in facilitating social reform because of their capacity to leverage governments as well as their human and financial resources. They also play an ideological role in introducing modern global values. In the disability field their aim is to mobilise policy makers, civil society and states around a new way of thinking about disability based on international standards and instruments such as the UN Standard Rules, ICF and the DCP. Even though they have the responsibility of supporting states in the de-institutionalisation process to developing a community-based system, their role is partially limited by the following factors:

- Disability is rarely mainstreamed into development programmes across all sectors,
- International actors continue to place disability into disability-specific initiatives rather than viewing disability as a human rights issue and a part of the overall development agenda.

Actors such as the World Bank and the EU have the leverage power to induce large institutional changes. According to their responsibilities they have to include disability issues as a part of overall development programmes so that it will be a part of the over-

arching social reform movement rather than as a separate issue where people with disabilities remain outside of mainstream society.

The need to mainstream disability into poverty reduction strategies

Despite its focus on the importance of social welfare reform and redirecting resources to vulnerable populations as critical parts of poverty alleviation, the World Bank, as an institution, has not mainstreamed disability into its overall development agenda. However, through a participative process in which various state and local civil society actors worked alongside members of the international community, the development of a Poverty Reduction Strategy Paper (PRSP) can contribute to the capacity building of local civil society as well as awareness raising of governments on disability issues.

In most of countries in the region, PRSPs were developed through a consultative process involving international actors, government and civil society. The PRSP can be viewed as an instigator for stakeholder collaboration on social development reform as it was the first time that so many groups were systematically consulted in the preparation of a comprehensive development strategy for the country. In Bosnia and Herzegovina, IC Lotos, a local DPO was included as part of the central coordination group for the overall PRSP consultative process as explained in spotlight 7.

Disability and the EU accession process

All the South East Europe countries are engaged at various levels in processes of accession to the European Union (EU), with the EU membership as a final objective. The driving factors for the EU in terms of accession is to work with political and economic institutions of pre-accession countries to comply with the EU Acquis Communautaire, or the Community Directive setting EU standards for legislation with which member states must harmonise while preparing their economy so that they can join the common EU market. Social reforms are a last priority in the EU accession process. An EU strategy towards disability exists, though it is not a priority in the framework of accession (Box 23).

However, the EU accession process has prompted many countries in the region to begin reforming the care system in line with European legislation and standards. For the region, Romania and Bulgaria have begun pre-accession reforms while Macedonia and Croatia have signed the Stabilisation Association Agreement (SAA) with the EU, a kind of road map for accession while the rest of the countries are due to enter the EU in the next 10 to 15 years⁷⁸.

⁷⁶ Inclusion Europe, European Association of Children with Disabilities and their Parents, and Republic Centre for Helping Persons with Mental Handicap - MESSAGE, "Human Rights of People with Intellectual Disability: Country Report Republic of Macedonia," (Inclusion Europe 2001): 25-27.

⁷⁷ Brookings Institution, "Arab Political Reform: Civil Society's Role," *Breakfast Discussion Transcript*, (May 2004): 23.

⁷⁸ Available at Department for European Integration website: <http://www.imo.hr/europa/publics/euroscope/es054.html>.

BOX 23

EU strategy towards disability briefing at 4th session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

Meeting conducted by Lisa Pavin Wolf - EU Commission Director for the Department of Employment and Social Affairs, 25 August 2004, UN Headquarters, New York

The EU approach to disability:

- The EU Commission does not recognise separate categories of disability but bases its strategy on individual needs and a more socially inclusive approach using the social model for understanding disability,
- The EU Commission wants to move from a disability specific policy to a more mainstream approach,
- Access is the core of the EU approach including the elimination of discrimination and access to rights,
- The EU takes a largely legalistic approach to mainstreaming and does not set out specific legislation for disability but mainstreaming it into all policies except regarding access to employment.

EU strategy: need for action at EU level:

- Reforming the approach to disability at the EU level brings about change in policy frameworks that can be carried out at member state level,
- Enlargement has caused a shift in welfare states and this makes it necessary to tackle the issue of disability as people with disabilities are an un-tapped resource because they are excluded from the labour market,
- Services need to be made available to people with disabilities so that they will be allowed access to employment,
- Japan and the U.S. are models for standards and accessibility and the EU will explore these models further.

Mainstreaming disability as a priority of the EU strategy:

- The aim of mainstreaming is inclusion and integration of the disability dimension in all policy areas in which the EU has competence and in all stages of policy development,
- The EU views access to employment as the most critical factor for inclusion and empowerment of people with disabilities.

EU global strategy for disability: employment is the main focus of the strategy and is approached by the following 4 themes

- Access to employment which will include the fight against discrimination based on reports from member countries on what they are doing for people with disabilities to curb employment discrimination - the EU will then disseminate best practices,
- Access to lifelong learning to increase people with disabilities' opportunities to become active members of society including programmes such as Socrates, Leonardo and E-learning,
- Access to new technologies that are barrier free and accessible to people with disabilities,
- Access to the public environment - the EU will issue a report on the principle of design for all putting inclusive design in all local policies.

SPOTLIGHT 7

DPO INVOLVEMENT IN THE PRSP IN BOSNIA AND HERZEGOVINA

IC Lotos - a DPO active in the PRSP consultative process in Bosnia and Herzegovina

IC Lotos is a local DPO in Tuzla made up of three components: an information centre on regional disability issues, an employment training centre, and a Day Care centre called Koraci Nade (Steps of Hope). IC Lotos has been active in lobbying on key disability issues such as greater accessibility promoting awareness raising and social policy reform. Recently, IC Lotos was an active participant in the development of the social reform agenda for the PRSP in Bosnia and Herzegovina. Because IC Lotos also operates a Day Care centre it allows them competencies in both policy reform and service provision on the local level. In addition, IC Lotos succeeded in securing cantonal support for Koraci Nade from the Cantonal Ministry of Social Affairs who will cover 70% of their running costs for salaries and activities. Still, the day care centre needs to secure funding for additional costs to ensure their sustainability.

IC Lotos was part of an NGO network in Tuzla called Reference Group made up of 54 members whose aim was to follow the policy and practices on a cantonal level regarding the reform process. From its involvement in Reference Group, IC Lotos was included on the NGO central coordination group for the PRSP consultative process in Bosnia and Herzegovina. The presence of an NGO focused on disability on this coordination body within the consultative process, put disability on the PRSP agenda.

During the consultative process in Bosnia and Herzegovina, there were 4 state conferences organised to compile the main fields of interest for NGOs. They came up with four issues that needed to be placed within the PRSP agenda on social reform:

- Education which includes disability as a part of this reform objective,
- Social protection which includes disability as a part of this reform objective,
- Corruption,
- Environment and agriculture.

From IC Lotos' involvement in the PRSP process, local DPOs in Bosnia and Herzegovina were pushed to be more involved in the overall PRSP process as well. The main result of this process was to build local DPO capacities in the following ways:

- Influenced traditional DPOs to change their approach to disability issues to a more human rights based one,
- Pushed DPOs to follow mainstream reform tools such as the PRSP in order to place disability issues on reform agendas,
- Opened the door for cooperation between DPOs who were traditionally fragmented.

The results of the PRSP consultative process in Bosnia and Herzegovina that impact the disability movement include:

- Strategic measures for tackling disability issues are included in the PRSP,
- Reforms are planned within the social protection sector, specifically lobbied for by IC Lotos,
- This consultative process enabled DPOs to form closer relationships with the government,
- Disability became more visible within the PRSP reform process - for example, 2 PRSP forums were held and in each forum, at least one person with disabilities was included in the official state delegation.



*Stop Barriers!
Accessibility
campaign*



*Koraci Nade
Day Care centre*

SPOTLIGHT 8

PARTNERSHIP IN MONTENEGRO

Day Care centre in Bijelo Polje, Montenegro

The first Day Care centre for children with disabilities in Montenegro was established in Bijelo Polje in June 2004 with the mission of providing opportunities for children with disabilities to be integrated in the community and to receive basic rehabilitation, education and to learn daily life skills. This initiative is unique in Montenegro, as it is based on partnership between:

- Ministry of Labour and Social Welfare,
- The Parents Association of Children with Disabilities in Bijelo Polje,
- The National Parents Association of Children with Disabilities in Montenegro,
- The local municipality of Bijelo Polje,
- The Centre for Social Work in Bijelo Polje.

The project was developed in collaboration with UNICEF, Handicap International, the Swiss Development Cooperation and Gemeinden Gemeinsam Schweiz, a Swiss charity-based NGO, with the aim of developing a Day Care centre co-managed by key local stakeholders. The planning process involved the following steps:

1. The project began with the formation of a working group made up of representatives of all the partners involved.
2. Three exchange visits were organised with Aurora in Bucharest, IC Lotos/Koraci Nade Day Care centre in Tuzla and Vladimir Nasor institution in Sarajevo, to share best practices on developing and building a Day Care centre.
3. The working group elaborated a project proposal in November 2003
4. The plan was agreed upon by the Ministry of Labour and Social Welfare and a pilot phase was planned for one year.

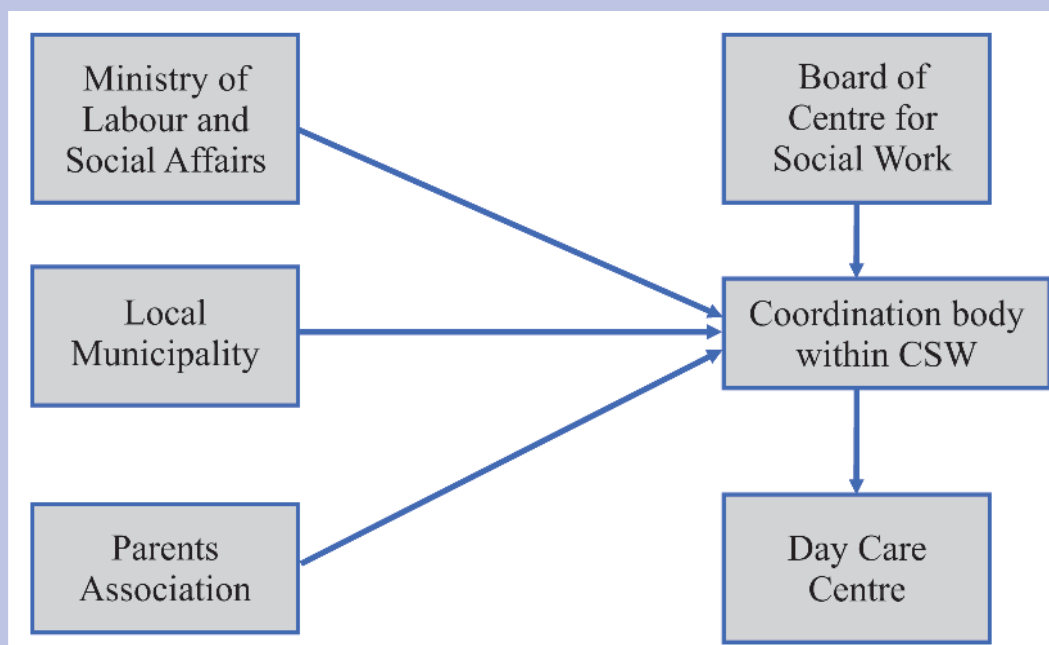
Building and managing a Day Care centre: a shared responsibility

During the pilot phase, the Day Care centre will be under the administration of the local Centre for Social Work in Bijelo Polje since most of the salaries and running costs will be paid by Ministry of Labour and Social Welfare. In order to ensure the partnership and involvement of the Parents Associations, strong negotiations took place and finally the following management structure during the pilot phase was agreed upon:

Management structure for Bijelo Polje Day Care centre

Training and awareness raising in the community on the new approach to disability

In addition to project planning, several trainings were organised with the working group as well as with the Parent Associations and other DPO's in Bijelo Polje on topics such as:



- Disability awareness,
- The Disability Creation Process,
- How to build awareness raising campaigns,
- PR development.

The staff of the Day Care centre has attended one training session in Slovenia as well as on the job trainings in Bijelo Polje along with Karin Dom Foundation from Varna. Several additional training sessions are planned during the pilot phase.

The Day Care centre in Bijelo Polje: a partnership best practice

- In order to ensure the sustainability of alternative forms of services, the state, local communities, parents, and Centres for Social Work should all have a stake in projects such as the Day Care centre in Bijelo Polje,
- Services should be a part of the overall welfare reform package owned and managed in partnership by cross-sector stakeholders in partnership,
- Monitoring and evaluation should be conducted in partnership as well with the involvement of all stakeholders including the state, parents, and people with disabilities.

Future Steps:

The Ministry has shown an interest in developing more centres like this one, but there is a need to change legislation on social policies, as well as having criteria and standards in order for future Day Care centres to become independent structures as alternatives to residential institutional care.



Training on awareness raising techniques, Bijelo Polje, 2003, conducted by the Associations of Students with Disabilities in Serbia and Montenegro



The Day Care centre is Open! Teachers working with children at the centre, Bijelo Polje, 2004



2. CHANGING PERCEPTIONS OF DISABILITY

UN Standard Rule 1. Awareness Raising (extracts)

States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

- States should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in an accessible form,
- States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation,
- States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.

Prejudices in society, including people with disabilities themselves, are one of the main barriers to full participation. People with disabilities are often seen as non-productive persons that need to be protected rather than supported. Feelings of fear and shame are the perceptions associated with disability leading to disempowerment, discrimination and exclusion. The practical implementation in shifting people's perceptions of disability needs to be approached by different stakeholders in three areas:

- Raising awareness on disability,
- Training professionals working in ordinary services,
- Producing comprehensive and relevant information on disability viewed through the holistic model that is accessible to people with disabilities.

2.1 Raising awareness on disability

Disability awareness-raising key priorities

- Sensitise the public around the new disability paradigm and new perceptions of disability,
- Make the issue of disability visible in society,
- Alert policy makers, professionals working with people with disabilities, media and politicians to the importance of viewing disability in terms of equal rights and opportunities.

Raising awareness is the first of the UN Standard Rules as it is considered a precondition for equal opportunities of people with disabilities. It is one of the first steps in mobilising a shift in the disability paradigm on individual, community, and global levels to new representations of people with disabilities, especially as the prejudices linked to disability come from ignorance and a lack of knowing the issues. Awareness raising brings visibility to the issue of disability, an issue that was largely hidden under the former system so that the public is sensitised to a new way of thinking helping to break down barriers and lessen stigmas.

Disability awareness-raising key target groups:

- People with disabilities,
- Their families,
- Their communities,
- Public service professionals,
- Decision makers.

Awareness raising campaigns should not be limited solely to raising public consciousness. They need to be targeted to key stakeholders in the change process including public service professionals, media, policy makers, families of people with disabilities and their communities; all of the people who have an impact on the lives of people with disabilities. As David Tobis writes, part of the strategy for making the transformation from over-protective care to community-based services is based on changing public opinion and mobilising community support⁷⁹.

Raising awareness amongst people with disabilities themselves: a critical part of awareness raising

Awareness raising must target people with disabilities themselves raising their consciousness from being passive to proactive as citizens and therefore, from beneficiaries to users of a community-based system. Policy makers, civil society, and families cannot assume that people with disabilities living under a paradigm that defines them as unequal citizens will be mobilised to take part in an enabling system without first changing their self-perception. A critical stake in mobilising support for change is, therefore, that people with disabilities view themselves as equal members of society with the right and responsibility to participate in decision-making and social life.

Today in the region, awareness-raising campaigns are largely implemented by DPOs or through pilot projects and initiatives. However, there is limited awareness raising amongst ordinary service professionals on topics such as inclusion, the holistic model for disability, and mainstreaming. Disability is still largely

⁷⁹ Tobis, *ibid*, 2.

invisible which is linked to the fact that information is not accessible within society, especially for people with disabilities.

Initiatives for change

Considering information and communication, the significant role of local organisations of people with disabilities (DPOs) including unions of organisations of people with disabilities should be pointed out. In the last decade, DPOs have helped to build successful community awareness campaigns at the local level throughout the region. Polio Plus, a local DPO in Macedonia, is an excellent example of strong awareness raising capable of presenting the issue of disability in the public sphere and challenging the public's perceptions of disability examined in spotlight number 9.

Changing representations of disability can also be approached through regional conferences, an excellent platform for awareness raising. For example, the Association of Students with Disabilities in Serbia organised a conference on disability and education with other countries in the region as well as Western Europe in order to mobilise students with disabilities in South East Europe and raise their awareness on inclusive education.

Looking ahead

The states in the region should establish awareness raising campaigns for schools and the public service system, relying on the expertise of people with disabilities as well as DPOs. An excellent opportunity for facilitating this awareness-raising programme would be for DPOs to develop partnerships with schools and universities in order to develop such sensitisation programmes. Another important approach to awareness raising is regional conferences that include associations and DPOs from Western Europe in order to gain insight into their experiences with the disability movement. Finally, it is important that DPOs share learning and skills on building awareness raising

campaigns with each other in order to understand the stakes and best practices.

2.2 Information and research on disability issues

The aim of information and research on disability issues includes:

- Providing accessible and relevant information to people with disabilities on their rights and available services,
- Informing policy-makers and other stakeholders on the situation of people with disabilities to help define the needed changes and monitor their implementation,
- Alert policy makers, professionals working with people with disabilities, media and politicians to the importance of viewing disability in terms of equal rights and opportunities.

The region has a severe lack of comprehensive information on all aspects of disability especially considering research on the lives of people with disabilities and the obstacles they face. Information collected by state social and health services is very limited, grouping people with disabilities into categories based on medical diagnosis, ignoring the majority of them and providing very little information on their actual needs. NGOs are the leading force in producing research and information on disability currently with little to no directive on the state level to further this effort. Moreover, throughout South East Europe, people with disabilities themselves are poorly informed about their rights or existing services available to them and this lack of communication further perpetuates their isolation and segregation from society. There is also limited reliable and precise data on the situation regarding access to information and communication for persons with disabilities in this region. In addition, there generally tends to be limited information about government activities and policy changes on disability issues (Box 24).

UN Standard Rule 13. Information and Research (extracts)

UN Standard Rule 13 States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

- States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities,
- States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities,
- States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities,
- States should facilitate the participation of persons with disabilities in data collection and research
- States should support the exchange of research findings and experiences,
- States should take measures to disseminate information and knowledge on disability to all political and administration levels...[...]

SPOTLIGHT 9

AWARENESS RAISING IN MACEDONIA

Polio Plus, a DPO in Skopje, Macedonia

Polio Plus is a DPO in Macedonia with a strong competency in media awareness raising and lobbying. One of their most provocative public campaigns was 'Nobody's Perfect' which depicts icons of beauty and celebrity such as Venus de Milo, Spider Man and Marilyn Monroe with prostheses. These images were placed on billboards throughout the city of Skopje with the words 'Nobody's Perfect' accompanying the images.

Nobody's Perfect is the second in a trilogy of campaigns that Polio Plus created to raise awareness of the general population as to the existence of people with disabilities in the wider community and their equal rights to full citizenship. The aim of this campaign was to challenge the social representations of disability. At the core of the 'Nobody's Perfect' campaign is a shift in the perception of disability from viewing people with disabilities as defective individuals to viewing disability as a part of the human experience.

At the same time, Polio Plus placed the images on billboards in strategic parts of the city to emphasise as well the need for media recognition of disability issues. Their actions refer to the European Congress on Disability declaration on disability and media which states:

"The Media should improve the portrayal of disabled people in mass media. More information on disabled people should be included in the media in recognition of the existence of human diversity. When referring to disability issues, the media should avoid any patronising or humiliating approaches but focus instead on the barriers disabled people face and the positive contribution to society disabled people can make once these barriers have been overcome" European Congress on Disability, Madrid. March 2002

Cross-section of Donors

Polio Plus received funding for this initiative from a cross-section of donors ranging from the private sector to the state, from local firms to multinational companies and international stakeholders including: The World Bank, Price Waterhouse, the city municipality, Share-SEE, Open Society Institute, Macedonian Telecom, and Skopska Beer Brewery. Therefore, not only international agencies are stakeholders in this awareness campaign but also the local municipality, multinational and local businesses, as well as civil society have a vested interest in the project.

While it is too early to judge the success of the campaigns, some indications that the initiative has achieved visibility include:



- **Media interest** - Radio Free Europe interviewed Polio Plus regarding the "Nobody's Perfect" campaign as part of overall review of initiatives made in the field of disability rights,
- **NGO and DPO interest** - Various local NGOs requested campaign media to use as part of their awareness raising initiatives,
- **Professional interest** - the Director of St. Erasmus, a rehabilitation orthopaedic hospital operating under the medical model, asked for sets of the campaign posters so as to display them in the hospital.

Awareness raising within the government: the formation of the Inter-Party Parliamentary Lobby Group (IPPLG)

Polio Plus not only targets the public in their campaigns, they launched an awareness raising initiative specifically targeted to the Macedonian parliament on the need to address disability issues on a state level. After successfully mobilising members of parliament, Polio Plus secured the commitment of 17 members of Parliament from different political parties to form the first inter-parliamentary lobby group in Macedonia based on disability rights. The goal of this group is improvement and promotion of the rights of persons with disability through lobbying. It will focus on disability rights and the introduction of a Disability Discrimination Act, a legal instrument that will lie

'Nobody's Perfect' accessibility campaign poster and billboards

across the whole of the legislature and serve as the reference point for disability issues.

Of the many legal initiatives submitted by the IPPLG one important declaration was unanimously adopted by parliament in July 2003, which morally committed it to work henceforth with reference and regard to the human rights of people with disabilities, drawing on international conventions and agreements, together with reference to EU legislation.

On a broader scale, the IPPLG has served as a useful role model for how state, government and parliamentary entities can and should work with NGOs on the overall aim of achieving harmonisation with the EU. In addition to promoting relevant examples of anti-discrimination and comprehensive laws from Europe such as the UK Disability Discrimination Act (1995), and international legal standards, the lobby group succeeded in raising awareness within the Macedonian parliament resulting in a "declaration for protection of the rights and dignity of people with disabilities".



BOX 24**Lack of public information on governmental activities on disability issues in Bulgaria**

One of the largest problems of disability policy reform is the lack of comprehensive information available to the community in regard to governmental activities on disability issues. In a survey conducted in Bulgaria on state policy, the majority of people with disabilities said they were not aware of government activity related to disability such as programmes and funds to assist people with disabilities, employment inclusion incentives or financial assistance policies. Despite this lack of knowledge, the survey showed that the majority of people with disabilities expect changes in the system to come mainly from the state rather than DPOs.

Source: Centre for Independent Living Disability - A Deficit or a Means for Survival: Disability Rights in Bulgaria, (Sofia: Centre for Independent Living, 2003).

Initiatives for change

As stated previously, DPOs and NGOs in the region are the major instigators for data and information collection on the situation for people with disabilities. The Centre for Independent Living (CIL) in Sofia produces a yearly survey on disability rights legislation in Bulgaria in collaboration with research institutes and various local NGOs. Along with reporting on disability rights in Bulgaria, the report makes an assessment of the situation of people with disabilities and evaluates how informed they are about their rights. The aim of the survey is to make an analysis of Bulgarian disability legislation in the framework of the UN Standard Rules. CIL Sofia recently published their third report on disability rights and the situation in Bulgaria in a report called, "Equal Opportunities through Access to Social Services". It makes a qualitative analysis of social services available to people with disabilities by asking users themselves how they view the services available to them as well as residential institutions, government policies and NGO activities towards disability issues. Finally, the report makes an economic analysis of the effectiveness of state resources on disability expenditures⁸⁰.

The Centre for Independent Living Serbia made a report on the "Specificity of Poverty among Persons with Disabilities" in collaboration with Oxfam, Belgrade (Box 25).

The survey on the situation of people with disabilities in the UN administered province of Kosovo conducted by Handicap International along with Gravir and HandiKos, a DPO in the UN administered province of Kosovo, illustrates how research can provide information on the environment of people with disabilities. Using the Disability Creation Process classification, it identified the main facilitators and obstacles encountered by the interviewees⁸¹. Spotlight number 9 explains the dynamic of this information initiative.

Looking ahead

Priorities for improving the field of information and communication regarding disability for the region include:

- **Comprehensive surveys should be conducted on the situation of persons with disabilities, on their needs and expectations, based on holistic models such as the ICF or the DCP,**
- **Databases should exist to collect information on the individual needs of people with disabilities. These databases should be mainstreamed into existing public services databases such as Centres for Social Work, education, and the Employment Bureau. This will help to identify if their services can reach people with disabilities,**
- **Improve the access to information for people with disabilities on their rights and available services. This will also provide them with the tools to monitor the change process.**

The state is also responsible for informing citizens on disability and care system policy reforms. Disability research programmes need to be funded by the state in order to understand the needs, obstacles and situation of people with disabilities. People with disabilities themselves should be involved in the collection, design and dissemination of this information with the participation and involvement of all stakeholders. Finally, and most critically, this information will provide the knowledge needed to communicate about disability according to the new disability paradigm.

2.3 Training of professionals working in services that concern persons with disabilities

The sustainability of community-based services developed in South East Europe over the last decade is tenuous in part due to the lack adequate training of professionals on the new disability paradigm. This can be done only through promoting a change in professional practices for all professionals working specifically with people with disabilities or those who

⁸⁰ Centre for Independent Living, "Disability - A Deficit or a Means for Survival: Equal Opportunities through Access to Social Services" (Sofia: Centre for Independent Living, 2003).

⁸¹ E. Bouffioulx, P. Castelein, G. Heris, M. Lemort, R. de Riedmatten: "Analysis report of the situation of people with disabilities in Kosovo" (GRAVIR, Handicap International, HandiKos, September 2002).

BOX 25**Report on the "Specificity of Poverty among Persons with Disabilities" carried out by Centre for Independent Living Serbia and Oxfam**

This project originated from CIL Serbia's involvement in monitoring the PRSP process in Serbia finding the need to address the issue of poverty and disability. The project was led and funded by Oxfam, Belgrade office. The research was carried out in three municipalities and included 180 people with disabilities of various types.

The main findings of this report show that:

- People with disabilities are one of the poorest groups among the poor citizens,
- The percentage of the poor among the people with disabilities is three times higher than among the other inhabitants.

The basic causes of poverty for people with disabilities as well as for the overall population are:

- Insufficient education,
- Impossibility of work engagement, particularly conditioned and strengthened by the specific causes of poverty for the disability population:
 - Additional expenses of disability,
 - Social exclusion,
 - Inexistence of necessary and adequate support systems.

If the "poverty line" is established as in the 2002 SLSP (Survey on the Living Standard of the Population) at 4,489 dinars per household member* then the income of 61,2% families of persons with disabilities is below the poverty line:

- 34% have an income ranging from 2,500 to 4,500 dinars per household member,
- 27.2% have an income below 2,500 dinars per household member.

The report makes a detailed analysis of the additional costs of disability and social exclusion of people with disabilities including very low accessibility to social services and affordability of services that facilitate independent living such as personal assistance. **Poverty is measured not only in income and economic dimensions but also in all of its aspects such as the dimension of accessibility of public utilities and services and the level of participation, and social exclusion.**

* Bogicevic, B., Krstic, G., Mijatovic, B., Milanovic, B. *POVERTY AND REFORM OF FINANCIAL SUPPORT TO THE POOR*, Ministry for Social Affairs and The Centre for Liberal-Democratic Studies, Belgrade, 2003, page 19.

are providing services that may concern persons with disabilities.

According to the holistic approach described in the UN Standard Rules, the main objectives for training professionals are:

- Professionals working in the disability field need to be trained on interdisciplinary teamwork, and on individualised and holistic rehabilitation tools,
- Professionals working with people with disabilities including educators, educational administrators and social workers need to be informed of the new disability paradigm and the principles of full participation,
- Mainstreaming disability into all ordinary services,
- People with disabilities should be included in training programmes and the development of new curriculum for public service training.

Under the institutionalised care systems in South East Europe, disability was considered as an individual pathology, to be cured by specialists such as defectologists and psychiatrists (physicians

specialised in physical medicine and rehabilitation). The training of rehabilitation professionals was and still is overspecialised and fragmented in terms of service delivery⁸². Even though the technical level of rehabilitation professionals trained in the former Yugoslavia and in Bulgaria was acknowledged as good, it was essentially based on medical diagnoses and the functional status of the person, with little attention paid to environmental factors and individual expectations. There has been little evolution on these aspects since then, partly due to a lack of opportunities for professional upskilling.

Most of the professionals working outside this specialised disability field do not receive any information on disability during their studies, and thus are reluctant to work with this category of clients, considering them as too fragile. For others like health professionals this information remains limited, and is still stamped with a very medical approach to disability. This is also the case within training programmes for social workers in countries from the former Yugoslavia which was the only country in Central and Eastern Europe to maintain

⁸² Pascal Granier, "Physical Rehabilitation Services in South East Europe", Disability Monitor Initiative, (Belgrade: Handicap International, 2004).

UN Standard Rule 19. Personnel Training (extracts)

States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities.

- States should ensure that all authorities providing services in the disability field give adequate training to their personnel,
- In the training of professionals in the disability field, as well as in the provision of information on disability in general training programmes, the principle of full participation and equality should be appropriately reflected,
- States should develop training programmes in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programmes.

training of social workers, or in other countries where it has been reintroduced after the fall of the communist regimes⁸³. As a consequence, professionals working in Centres for Social Work are generally lacking awareness on how to support persons with disabilities (Box 26). Procedures for achieving rights from state institutions are complicated, time consuming. In a survey on "Persons with Disabilities and the Environment" conducted in Serbia and Montenegro in 2001, for example, it shows that slow administration procedures are one of the main obstacles for people with disabilities to achieve their rights⁸⁴.

Initiatives for change

Despite this general lack of adequate training of professionals, some changes have begun. In the Medical Faculty of Pristina, in the UN administered province of Kosovo, the bachelor programme for physiotherapy, established in October 2001, opens up to the new disability paradigm. During their 3-year programme, students attend a 20-hour course on the various approaches to disability, 20 hours of community-based rehabilitation, and a 50 hour course on occupational therapy⁸⁵. In Serbia the students from the physiotherapy school received an introductory lecture on the DCP⁸⁶ in 2004.

The profession of occupational therapy, which takes a holistic approach to disability emphasising the notions of participation and environment, was up to now almost absent from the region (Box 27). However, there are now hints that it is beginning to develop.

Beside these few examples, many initiatives can be found in the region regarding professional upgrading and continuing education. The introduction of CBR services in some countries has been accompanied with training of these professionals by organisations, like Queen's University in CBR centres in Bosnia and Herzegovina, or Handicap International for HandiKos community workers in the UN administered province of Kosovo (see part II, 3.2). Additionally, in some places

few professionals gathered around a common project of proposing alternative services for people with disabilities, often in collaboration with associations of persons with disabilities or associations of parents. In some cases, these groups have collaborated in establishing Day Care centres or community-based services, often with international support. Some of these structures, like Aurora in Romania or Karin Dom Foundation in Bulgaria (see part II, 3.2 and 5.3) have developed their capacities into resource and training centres, and propose literature and trainings to other professionals. Karin Dom also became a clinical placement location for undergraduate physiotherapy students, which is an interesting opportunity to sensitise future professionals and to make a link with training structures for rehabilitation professionals. Some associations of professionals like the young Croatian Society of Physiotherapists⁸⁷ promote a higher quality of services through the evidence-based approach and the holistic approach to disability. They propose professional trainings and publications for professionals.

Initiatives for sensitisation and training of professionals (teachers and social workers) working in ordinary services have been conducted in some locations. In 2003, within the project "*CBR in the Sandzak region - family and children component*" a first needs assessment and registration process was conducted in Serbia in the municipality of Novi Pazar by the local Centre for Social Work. The aim of this initiative was to identify children and adults with disabilities, document their individual needs and to provide information on existing services and support in the local community. As a part of this project, professionals working in the CSW attended a workshop on disability awareness training where social workers were sensitised on the specific needs and rights of people with disabilities⁸⁸. However, there are still a large number of professionals working in institutions and Centres for Social Work who are extremely resistant to shifting the paradigm for disability to the social model.

⁸³ Tobis, *ibid*, 13.

⁸⁴ Center for Policy Studies, and Handicap International, "Persons with Disabilities and Environment," Research project (Belgrade, 2001).

⁸⁵ According to the curriculum for professional physiotherapy studies at the University of Pristina, Medical Faculty, Physiotherapy Branch, (Pristina: July 2001).

⁸⁶ Performed by a trainer from Handicap International in Belgrade on May 12, 2004.

⁸⁷ Information available at: www.hzf.hr

⁸⁸ Refer to Handicap International South East Europe final report "CBR project in Novi Pazar, Serbia, implemented by Handicap International and UNICEF 2003-2004." (Belgrade: Handicap International, 2004).

Looking ahead

As stated earlier, there is a need to shift away from a system that used to train only disability specialists based on a medical approach, towards training all professionals working in ordinary services (such as social workers, teachers, and nurses) on disability

issues. This shift will ensure that "persons with disabilities receive the support they need within the ordinary structures of education, health, employment and social services⁸⁹". These professionals need to be able to draw up interdisciplinary individualised action plans, based on a coordinated assessment of the needs of people with disabilities, taking into consideration

BOX 26

The need for mainstreaming of disability: the case of Centres for Social Work in Bosnia and Herzegovina

Centres for Social Work (CSW) in Bosnia and Herzegovina (BiH), as in most of the countries of the region, are a key element in the social protection system. They are in charge of the implementation of the laws and policies related to social protection through ensuring gate-keeping and the delivery of cash assistance and of outreach social services for vulnerable groups.

From August to November 2003, an assessment, co-funded by Handicap International and UNICEF, regarding the possibility to "mainstream disability issues including landmines victims' assistance within the social policy reform process in Bosnia and Herzegovina (BiH)", was carried out. In that context, 24 Centres for Social Work have been assessed on their activities within the disability field.

During the assessment, besides the obvious lack of funding to fulfill their obligations defined in the legislation, it appears clearly that CSWs do not have the capacity to serve clients with disabilities in regard to infrastructure, staff and activities:

- Among the 24 CSWs assessed only 4 were accessible,
- Despite the good will expressed by the staff members, most of them have a medical and charity approach to support people with disabilities. Both administrative and technical staff members had not received any training for the development of skills and knowledge in a comprehensive and holistic approach to disability,
- Data management regarding people with disabilities is weak as the CSWs are not pro-active in the assessment of the needs of people with disabilities. According to interviews with DPOs, many people with disabilities remain invisible within the system. In addition, due to the fragmentation of the legal framework in BiH, the various CSWs do not follow the same criteria, or definition for similar entitlements. This leads to the impossibility at the cantonal, entity and national level to rely on relevant data necessary to develop consistent policies.

As a consequence, the CSWs do not properly fulfil their mission of support to people with disabilities according to the following indicators:

- There are very few outreach services for people with disabilities,
- Only seven CSWs have developed concrete cooperation with DPOs or community-based service providers,
- The gate-keeping mechanisms are based on a medical assessment rather than needs-based assessments and therefore, do not allow for an optimal use of the resources available. Furthermore, there is a lack of transparency in the attribution of benefits,
- In most of the cases CSW staff members rely on residential care as an answer to the problems formulated by families of children with disabilities rather than looking at the options available within the community,
- CSWs are not pro-active in the development of community-based services or reform of the system that could allow them to provide better services.

The seven CSWs that have concrete cooperation with DPOs or new community-based service providers tended to develop a better understanding of the needs of people with disabilities. In addition, they tend to be more pro-active in the community. For example, these CSWs took part in activities such as the development of inclusive education initiatives or the facilitation of transportation between the municipalities to avoid placement in boarding schools. These initiatives rely mainly on a higher level of awareness from the director of the centre, even if, as is often the case, they are still grounded in a medical approach to disability. **This shows that awareness raising and appropriate training of staff members can have an immediate impact on way the services are delivered, despite the current shortage of resources.**

⁸⁹ United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Introduction see the Annex of this report.

BOX 27**The slow but necessary development of occupational therapy in South East Europe****What is occupational therapy?**

"Occupational therapy is a profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation. Examples include teaching new techniques and providing equipment which facilitate independence in personal care and reducing environmental barriers." (Definition from the World Federation of Occupational Therapists, available at: www.wfot.org.au)

The current situation of occupational therapy in South East Europe

The profession is currently almost absent from South East Europe, except in Serbia which is the only region with a high school for occupational therapists. However, even in Serbia, out of 550 occupational therapy graduates, only approximately 150 are employed as such, and their field of work is often narrowed down to psychiatry. In Bosnia and Herzegovina some occupational therapy programmes were implemented in the frame of Community-Based Rehabilitation programmes, but the profession does not officially exist. In neighbouring countries, Slovenia is the only country where occupational therapy is well established and recognised. In Croatia an occupational therapy high school programme was established in 1986, but since then only 45 graduates out of 186 work as such*. In Romania, Bulgaria and Hungary occupational therapy does not exist yet.

The early beginnings of a development of the profession in the region

Romania is about to establish bachelor graduate training in occupational therapy in Bacau, Timisoara and Oradea with the support of the European Network of Occupational Therapy in Higher Education (ENOTHE). Bulgaria and Hungary are also associated to this programme, with the aim of introducing occupational therapy in their own educational systems. In Serbia, the Association of Occupational Therapy was created as an independent association in 2001, with the objective of promoting the development of the profession in Serbia consistently with European professional and educational standards. One of its representatives took part in the 10th annual meeting of the ENOTHE on September 2004.

(Precise information about this project available at: <http://www.enothe.hva.nl/projects/tuning/fpypdee/index.html>)

* *Interview with the Secretary of the Serbian Association of Occupational Therapy, Belgrade May 12, 2004*

personal factors, environmental factors and life habits/expectations. The training of professionals needs to be based on modern holistic approaches to disability (such as the DCP or the ICF) and international instruments (such as the UN Standard Rules and the Council of Europe Recommendation R (92) 6).

It is imperative that training and sensitisation programmes provide support to these professionals to help them with the transition towards an inclusive approach. Professionals and educators working with people with disabilities will need support as they learn new skills while reassessing their professional background in order to accept new values and a new approach.

To hasten the dissemination of the new paradigm within the education of professionals, synergies should be developed between universities and high-schools from various fields, service-providers that promote the community-based approach, local and international NGOs, and most importantly the organisations of persons with disabilities (DPOs). These exchanges would build up a local interdisciplinary resource network, which would ensure that the training of professionals relies on the expertise of people with

disabilities themselves. This network would be a vector of regional and international exchange, ensuring the appropriation of the new paradigm by various universities and academic institutions. It would also ensure the continuous upgrading of professional and pedagogical tools through research and information sharing.

Attitudes based on segregation and the medical model by professionals, families, policy makers and people with disabilities themselves are one of the largest barriers to change. Changing perceptions of disability is a long process that involves not only awareness raising campaigns but comprehensive research and information on disability made available to all as well as new methodology for training public service professionals based on the holistic approach. There are examples in the region where the approach to changing minds is being achieved in a holistic manner beginning with research and information followed by awareness raising and training on the new disability paradigm. The following example shows a best practice using a multi-pronged and comprehensive approach (Box 28).

BOX 28

The promotion of inclusive education initiative in South East Europe: a comprehensive approach to raise awareness and change representations of people with disabilities

The Associations of Students with Disabilities in Moldova, Macedonia, Serbia and Montenegro joined together to take a regional approach to promote inclusive education. The initiative began in December 2003. Using both information and research along with media campaigns is an excellent way to approach changing the dominant perceptions of disability. In addition, the regional approach to promoting new ideas has an added value as it facilitates sharing experiences and resources in the process of shifting the paradigm. The project has several phases:

1. Phase one: gathering information and research

- The project began with a wide-scale survey on students with disabilities attending university based on interviews with students themselves in all three countries,
- An analysis of legislation related to education was made in all three countries using a team of lawyers with disabilities.

2. Phase two: media campaigns

- A media campaign was organised to promote the results of the survey to the public as well as to policy-makers,
- The associations created a list of amendments and propositions for changing legislation based on the legal analysis and presented to various ministries.

3. Phase three: lobbying

- Lobbying activities were carried out within the ministries in all three countries based on the findings and research that was gathered,
- Lobbying university administrations was carried out using the findings in the surveys to communicate their demands.

Conclusion

While it is too early to tell what impact this initiative has had, the approach used to change minds and raise awareness around the inclusive paradigm is multifaceted using information on the situation for students with disabilities as well as legal analysis on education to convey the message.

Source: Interview with the Association for Disabled Students, Serbia, Belgrade, October 2004.

SPOTLIGHT 10

INFORMATION AND RESEARCH IN THE UN ADMINISTERED PROVINCE OF KOSOVO

Survey on the analysis of the situation of people with disabilities in the UN administered province of Kosovo - 2002

Objective of the survey

In December 2000, a Disability Task Force was established in Kosovo, comprised of representatives from political institutions and civil society, with the mandate to work out a disability policy framework using an inter-sectoral approach. However, the absence of comprehensive information on the situation of people with disabilities was a major obstacle in that process. The objective of the survey was thus to collect reliable information about the needs of people with disabilities in Kosovo and of the main obstacles they have to face in everyday life, as a basis for both formulating policies and planning services.

Methodology

The survey was conducted using a tool named "**Measurement of the Quality of Environment**" (MQE) (Fougeyrollas & al 1998), based on the Disability Creation Process classification (DCP). The MQE allows for collecting the opinion of people with disabilities on their environment. According to the DCP:

- An **environmental factor** is a physical or social dimension that determines a society's organisation and context,
- A **facilitator** refers to an environmental factor that contributes to the accomplishment of life habits when interacting with personal factors (impairments, disabilities and other characteristics of a person),
- An **obstacle** refers to an environmental factor that hinders the accomplishment of life habits when interacting with personal factors.



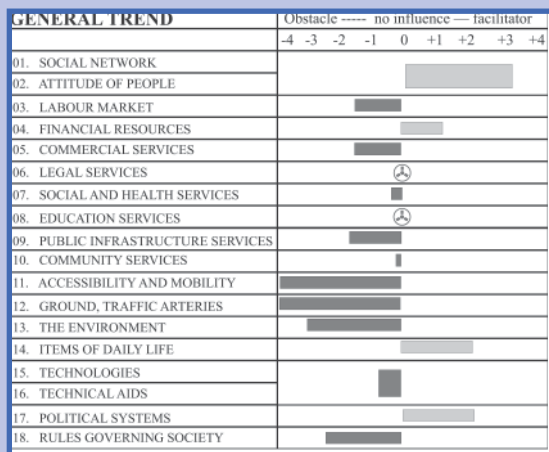
Family in Kosovo who participated in the assessment

During the preliminary phase, the questionnaire was adapted to the Kosovo environment, to end up with 96 items, belonging to 6 main categories of environmental factors. For each item, 5 answers could be given to qualify the environmental factor, ranging from a major facilitator to a major obstacle. To overcome the absence of centralised data on persons with disabilities, the sample was created according to the cluster method. 400 persons were selected at random, to get a final number of 391 valid questionnaires. 16 interviewers were trained on the use of the MQE, and performed the field interviews.

Results

Analysis of the 391 questionnaires revealed that the environmental factor perceived as the **main facilitator** was the close **human environment**. The **support of close family** was perceived as a facilitator for 68% of the respondents (the support received from the rest of the social environment has no influence for 45% of them), while the **attitudes** of the human environment was considered as positive, essentially for the family (80%) and for the friends (77%).

The **main obstacle** appeared to be the **built environment**, with the accessibility of public buildings being an obstacle for 65% of the interviewees, and the accessibility of roads for 82%. The survey also revealed the **limited access of people with disabilities to education**, with 38% of the persons surveyed who did not start or complete primary school. The **labour market also was a major obstacle**, and 96% of the respondents were unemployed at the time of the survey.



Conclusion

Despite its methodological limitations due to the difficulty in constituting a representative sample, the survey has for the first time in Kosovo allowed for the reflection of opinions and perceptions expressed by people with disabilities or their relatives on their environment in Kosovo. It gives an overview of the existing barriers / opportunities within this environment, highlighting those who seem to have a bigger impact on their social participation.

Source: E. Bouffioulx, P. Castelein, G. Heris, M. Lemort, R. de Riedmatten; Analysis report of the situation of people with disabilities in Kosovo, September 2002; GRAVIR / Handicap International.

3. COMPREHENSIVE AND ANTI-DISCRIMINATION LEGISLATION

UN Standard Rule 15. Legislation (extracts)

States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities.

- National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation.

To accompany the development of an enabling system, especially with regards to its mainstreaming and inclusive dimensions, there is a need to develop anti-discrimination and comprehensive cross-cutting legal frameworks for equal opportunities that will force changes in the environment by allowing people with disabilities to exercise their rights. The stakes in the region for establishing progressive legal tools for equal opportunities include:

- Implementing comprehensive anti-discrimination legislation guided by the principles of equal opportunities with enforcement and monitoring mechanisms,
- Anti-discrimination frameworks should use international standards and legal instruments such as the UN Standard Rules and the UN conventions on human rights, the Council of Europe charter and EU convention,
- Comprehensive legislation should establish an

Ombudsman to regulate complaints and report on discrimination as well as a commission or council for the rights of people with disabilities that participates in law suits.

Anti-discrimination legislation is seen as essential for the disability movement because it is a means of protecting people with disabilities against discrimination perpetuated by social structures and institutions, especially relevant in South East Europe where the disability paradigm is based on segregationist policies⁹⁰. However, legislation without enforcement mechanisms has little chance of making an impact. Anti-discrimination legislation is especially relevant in the region because if adopted by the various states, it has the power to change the situation for people with disabilities immediately, before the transition to an enabling system is complete.

The Americans with Disabilities Act (ADA) is an

BOX 29

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) adopted in 1990 addresses access to the workplace (title I), state and local government services (title II), and places of public accommodation and commercial facilities (title III). It also requires phone companies to provide telecommunications relay services for people who have hearing or speech impairments (title IV) and miscellaneous instructions to Federal agencies that enforce the law (title V). Regulations issued under the different titles by various Federal agencies set requirements and establish enforcement procedures.

The ADA was one of the first pieces of disability anti-discrimination legislation with mechanisms for enforcement. The ADA was developed by the National Council on Disability, which in 1989 published *Towards Independence*, recommending comprehensive civil rights for people with disabilities. The ADA gives civil rights protection to disabled people. It guarantees equal opportunities in employment, public accommodation, transport, state and local government services, and telecoms. One of the innovative aspects of this act is that it protects disabled people; people in a situation of disability or "regarded" as disabled; and people with a relationship or association with a disabled person. In addition, the ADA had the benefit of having enforcement agencies from the start, including the US Equal Employment Opportunity Commission and the US Department of Justice.

⁹⁰ Kathryn Ellis, "Human Rights, Professional Practice and Social Care: the Findings of a Small Scale Research Study," in *Disability Studies: From Theory to Practice*, (Lancaster University, July 2004): 1.

BOX 30**EU anti-discrimination legislation - briefing at 4th session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities**

Meeting conducted by Lisa Pavin Wolf - EU Commission Director for the Department of Employment and Social Affairs, 27 August 2004, UN Headquarters, New York.

The history of EU work on anti-discrimination legislation:

- In 1996, the EU issued a commission on equalisation of opportunities for people with disabilities moving from a passive to a proactive approach - a shift in paradigm from special treatment to a rights based approach,
- In 1997, the EU Council Summit amended the legal framework under article 13 of the EU treaty to include anti-discrimination legislation on the grounds of disability.

The two directives of non-discrimination in EU legislation:

- **Race:** Non-discrimination legislation based on race covers access to goods and services, social protection, social welfare, social services, and employment,
- **Gender, age, disability and sexual orientation:** Non-discrimination legislation based on these categories protects people only in terms of employment (Note: The EU's stance on anti-discrimination legislation regarding disability will remain focused **on access to employment**).

The directives of non-discrimination regarding disability in employment are based on article 13 of the EU treaty underpinned by the following terms:

- **Direct discrimination** occurs when a person is or would be treated less favourably than another
- **Indirect discrimination** occurs when conditions, provisions, or criteria are put in practice that put a person with disabilities at a particular disadvantage than others,
- **Harassment** is defined as placing obligation on employers to adapt the workplace and work situation to accommodate the needs of people with disabilities so that they can compete in the labour market,
- **Reasonable Accommodation** is not seen as a positive measure by the EU as it is not given at the discretion of the employer but as an obligation,
- **Burden of Proof** obliges the employer to prove that they chose a person without disabilities before a person with disabilities and must prove that this person has skills beyond the person with disabilities.

excellent example of a comprehensive legislative framework based both on positive measures for equal opportunities as well as an anti-discrimination mechanism. It is an umbrella law that systematically checks other laws to ensure they are in compliance providing a complete legal framework for non-discrimination (Box 29).

The EU has anti-discrimination legislation regarding disability as well. However, it is focused mainly on inclusion of people with disabilities in the workforce and is, therefore, not a comprehensive legal act (Box 30).

EU anti-discrimination directives do not come into effect as national legislation right away. Member states are given time to adopt these directives into their state legislation but there is no provision for harmonisation on the national level at this point.

3.1 Initiatives for change

Various initiatives exist in the region to develop anti-discrimination or comprehensive law. In Macedonia, **Polio Plus** together with Inter-Party Parliamentary Lobby Group (IPPLG) is working on drafting *lex generalis* (a comprehensive law) which consists of general provisions concerning the rights of people with disabilities. In this *lex generalis* special emphasis will be placed on:

- Mechanisms to regulate the protection of the rights listed in the law (i.e. establishing a Disability Rights Commission and a governmental body),
- The creation of funds especially for the implementation of these mechanisms.

This comprehensive law will produce several *lex specialis*, which will elaborate various spheres of interest for people with disabilities in the Republic of Macedonia.

In Serbia, a comprehensive anti-discrimination legislation is currently being drafted by legal experts on disability, many of whom are people with disabilities. It is known as the *Special Law on Anti-discrimination of People with Disabilities*. The law is based on anti-discrimination as well as equal opportunities measures with mechanisms for enforcement. It includes the establishment of three organs to regulate the law including:

- An Ombudsman to defend the rights of people with disabilities, reporting and participating in law suits,
- A Council for Equality of People with Disabilities elected by government to review current laws and ensure they are in compliance and act as an advisory body to the government,
- A Voluntary Examiner of Discrimination who reports on acts of discrimination.

BOX 31**Access conference: international annual accessibility conference in South East Europe**

Access 2004, in its fourth year, is an annual international conference on accessibility issues. The first conference was initiated and organised by CIL Serbia in 2000 and is now becoming a traditional event marking the celebration of 3rd December, the International Day of the rights of people with disabilities. In 2004, the Access Conference was organised by CIL Serbia in collaboration with the Association of Disabled Students and Handicap International South East Europe and sponsored by Share-SEE.

Last year's conference, Access 2003 (also sponsored by Share-SEE), was the third annual gathering held in Belgrade and focused on accessibility as a human right. Over 100 participants gathered at the conference, consisting of accessibility and disability specialists, public service professionals, local DPOs, relevant ministries from the Serbian Government and international organisations from around the region as well as Western Europe. There were three main topics discussed:

- Universal design (see glossary),
- Campaigns to promote an accessible environment in the region,
- Local initiatives for the creation of an accessible environment - best practices in South East Europe shared.

Several conclusions were drawn from the working groups as critical stakes for improving accessibility in the region:

- Regional cooperation is needed to implement European accessibility standards as part of EU accession,
- DPOs should work to raise awareness and influence architects and engineers on accessibility,
- DPOs need to work in cooperation to develop a comprehensive strategy for universal design so they can lobby for changes in legislation on urban planning and construction.

This year's Access conference is divided into three topics: Enforcement of rules on accessibility to the physical environment, access to education, and access to new technology and information. The conference gathers disability experts on accessibility from 12 countries around the region and Western Europe, including representatives from the Council of Europe, European Disability Forum and DPI, with the objective of sharing best practices in accessibility through presentations and workshops, and developing plans for further actions to be taken in the area of accessibility.

This Special Law was drafted by the Institute for the Advancement of Legal Studies and by people with disabilities who are legal experts. The draft is currently being discussed by DPOs and the Ministry of Labour, Employment and Social Affairs of Serbia⁹¹.

3.2 Looking ahead

- Anti-discrimination legislation should be drafted in collaboration with legal experts on disability, DPOs and people with disabilities,
- There should be mechanisms built into the legislation for enforcement and compliance
- Anti-discrimination legislation should facilitate participation in all aspects of social life including, education, employment, social protection, access to

goods and services,

- The creation of different bodies that regulate the enforcement of the law and civil procedures such as an Ombudsman as well as a disability council are essential.

Key issue: accessibility

Tied to anti-discrimination is the need for enforcement of regulations so that the environment, including the built environment, technology and communication, is open and accessible to people with disabilities. An accessible environment is a key element in changing the approach to disability. An accessible environment will help support people with disabilities to move within the community and by their presence as

UN Standard Rule 5. Accessibility (extract)

States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication.

⁹¹ Damjan Tatic, legal expert on disability involved in the drafting of the Special Law on People with Disabilities, interview, Belgrade, November 2004.

"ordinary citizens" it will help to bring a change in people's minds.

Currently, none of the countries in the region have an accessible environment. Even when legislation exists and promotes accessibility norms, the regulations are not enforced. Generally, the professionals dealing with the built environment or information technology are not trained properly on accessibility and sometimes not even aware of the barriers that they are setting up everyday.

There are many civil society initiatives in the region on accessibility to the built environment, communication and technology. They are generally small in scale lacking the resources and support to make widespread changes in accessibility.

Throughout the region, DPOs have organised campaigns at the community level demanding greater accessibility. One such example took place in April 2004 in Tirana, when 15 DPOs and parents'

associations organised a two-day awareness campaign on accessibility in partnership with local media wherein they produced ramps and posters illustrating the lack of access to public buildings. As a result of this campaign, the participants were asked to elaborate a draft law on accessibility as a part of draft law on social protection.

Regarding access to information, in the UN administered province of Kosovo, the OSCE is supporting an initiative on access to communication for the deaf community, one of the most uninformed communities in the region because little to no media is translated into Sign language. The initiative is based on developing a TV programme in sign language set to start in mid-November.

One of the most comprehensive initiatives in the region is **Access**, an annual international conference held in Belgrade which monitors the evolution of accessibility issue in the region (Box 31).

4. REDIRECTING RESOURCES

As shown in part 2, community-based services prove to have an enabling impact on the lives of people with disabilities. Therefore, an essential part of reforming the care system is orienting a country's financial and administrative resources towards community-based approaches and supportive social security measures that are not a disincentive to inclusion. The high cost of transition and the prioritisation that it implies makes it critical for states to drive the change especially as community-based service provision proves to be more cost-effective⁹².

Redirecting resources implies a reorganisation of the care system management structures in order to allow people with disabilities to exercise their rights by creating efficient regulatory systems so that the service delivery is based around needs-based assessments directing the beneficiaries to the appropriate services. Furthermore, building financial incentives for quality services that are evaluated on effective delivery of service and include users in the development of quality practice is a critical stake in the change process. Some of the main reform mechanisms that need to be implemented in order to redirect resources include:

- **Gate-keeping** for better targeting of beneficiaries through needs-based assessments,
- **Disability pension reform** to fill the gap during the decentralisation process,
- **Quality standards** with formal accreditation and licensing processes.

4.1 Gate-keeping

Gate-keeping, is essentially an administrative tool for managing people's needs by using criteria in their assessments, which determines whether services are provided, as well as prioritising outcomes according to available resources⁹³. It is therefore a key mechanism for better targeting the use of services. In the de-institutionalisation process, there is a need to reform the gate-keeping system, in order to divert beneficiaries away from initial entry to the residential care system and orient them towards community-based services. To that end, the decision-making framework needs to be based on individual needs assessments rather than impairment-based ones. The state has the responsibility to create gate-keeping policies so that the analytical framework behind decision-making within the care system fosters the following principles:

- Promotes strategies to divert beneficiaries, especially children with disabilities away from

institutional care,

- Pro-active approach allowing beneficiaries to choose and have control over their decisions,
- Transparent decision making processes,
- A shift from the medical model to social model for assessing a beneficiaries' needs,
- Decision-making processes that allows a beneficiary to participate⁹⁴.

Within Western Europe, there is increasing emphasis being placed on the assessment process in the negotiation of social rights. Gate-keeping is a crucial time for people with disabilities to get access to services that meet their needs⁹⁵ because it regulates an individual's access to social services and the eligibility criteria for this assessment. Eligibility criteria governing access to the care system grounded in human rights supports the empowerment of people with disabilities. As suggested by Vesna Bošnjak, the former advisor to the former Ministry of Social Affairs in Serbia on the reform of the social welfare system, it is critical that the entranceway to the care system is based around client-based needs and the human rights paradigm when moving toward a holistic approach to disability. Gate-keeping, if based upon the principles of human rights and equal opportunities, can also help to build a new human rights culture amongst public service providers⁹⁶.

As described in part II, for most countries in the region, the Commissions for Categorisation were the main decision-making bodies for children with disabilities, directing them towards mainstream schools, special schools or a residential institution. The criteria for categorising a child were largely medical as the child was categorised according to their physical and mental condition rather than assessed in terms of their needs and the environment in which they lived. In most cases, the categorisation process does not allow for re-assessment later in the child's life, with the exception of rare cases, meaning that there is no room for a child with disabilities who may develop or change their capacities, to be re-assessed allowing for their status to be changed by the categorisation commission⁹⁷.

Initiatives for change

There are some examples of reforms of gate-keeping mechanisms beginning to develop in the region. For example, the reform of the Commissions for Categorisation currently waiting to be passed by the Ministry of Sports and Education in Serbia is an interesting example of a reform that has the potential

⁹² Tobis, *ibid*, 37.

⁹³ Kathryn Ellis, *ibid*, 6-7.

⁹⁴ Andy Bilson and Judith Harwin, "Gate Keeping Services for Vulnerable Children and Families" in *Changing Minds Policies and Lives*, (Florence: UNICEF Innocenti Centre and the World Bank, 2003): vi.

⁹⁵ Kirsten Rummery and Caroline Glendinning, "Negotiating needs, access and gate-keeping: development in health and community care policies in the UK and the rights of disabled and older citizens", *Critical Social Policy* Vol. 19(3), (London: Sage Publications, 1999): 341.

⁹⁶ Kathryn Ellis, *ibid*, 3-5.

⁹⁷ There is a possibility for re-categorisation upon demand of the family to the Commission, but it was not encouraged and not put in practice.

to make a significant impact on individuals' lives. The proposed reforms call for a complete transformation of the assessment process for children with disabilities entering primary school so that the commissions move from a negative assessment to one that is based on a child's capabilities using the DCP as the fundamental guiding principle⁹⁸. This is a significant example of how reforming gate-keeping can better answer the needs of beneficiaries (Spotlight 10).

4.2 The need for quality standards, licensing and accreditation

In addition to changing the way in which beneficiaries enter the care system, there is a need to work towards increased quality standards in the region, and to push the different states to take the responsibility to include these "new" alternative types of services within the overall welfare system. This is particularly important because as a part of decentralisation, local and municipal governments have been granted increased autonomy in administration and implementation of social services while NGOs and community organisations have begun to take on the responsibility of providing services as well. Critical for sustaining these newly formed community-based services is the implementation of:

- Quality standards based on international standards and classification of disability such as the and UN Standard Rules, the DCP and ICF,
- Formal legal accreditation and licensing processes to ensure that quality standards are used in practice within public services,

- Sub-contracting by the state to local service providers and access to public funds for NGOs or DPOs providing accredited services.

Quality standards provide a set of criteria that can be used to monitor the management and provision of services, the quality of services as well as their outcome. They ensure equitable and transparent transfer of services to the beneficiary⁹⁹. Accreditation and licensing are regulatory mechanisms for implementing standards and ensuring the user a certain level of quality for the services provided. **Licensing** is a mandatory process by which the government grants permission to be a service provider after finding that the service provider has obtained a certain degree of competency that is required. It ensures that service providers have obtained the minimum level of standards to provide certain services. **Accreditation** is a voluntary process that offers the service provider recognition for obtaining standards of excellence defined by an accreditation agency.

Licensing and accreditation play another important role in enabling the state to subcontract NGOs or private local providers who complete the accreditation and licensing processes. This process also helps to establish a more client-based system in which the client or the user chooses services according to whether or not they are licensed and will therefore provide better quality services. This is especially important as a great challenge in redirecting resources to a more client-based system is the inexistence of a real market for services in much of South East Europe¹⁰⁰.

BOX 32

What needs to be included in quality standards for services for people with disabilities or mainstreamed services

Any definition of quality standards for services for people with disabilities should be based on respect for human rights of people with disabilities and different UN Conventions such as the Rights of the Child.

- Standards must ensure the client or its representative the right to be informed about the range of services available to them and the right to choose the most appropriate service,
- Standards must ensure that the users have the right to be included in the creation as well as the evaluation of services,
- Standards must promote social integration, social participation in order to prevent an isolated structure,
- Standards should ensure a flexibility of services in order to allow for new applications of approaches, and to adapt to the needs of the users,
- Standards should ensure that clear procedures are laid down for activities, tasks and staff and that they are regularly updated,
- Standards should be re-viewed and re-evaluated on a regular basis.

Source: Recommendations from the participants in the 2nd Regional workshop on Community Based Service, organised by Handicap International South East Europe, in Belgrade 2004.

⁹⁸ Refer to the definition of the Disability Creation Process in Part I Box 4.

⁹⁹ Bilson and Harwin, *ibid*, iii.

¹⁰⁰ Louise Fox and Ragnar Gotestam, "Redirecting resources to Community-Based Services - A Concept Paper," (Florence: UNICEF Innocenti Centre and the World Bank, 2003): 9.

SPOTLIGHT 11

GATE-KEEPING REFORM IN SERBIA

Reform of the Commissions for Categorisation in the Republic of Serbia

Commissions for Categorisation, as one of the main entry points into residential institutions for children with disabilities, were considered a priority in the reform of the social protection system. Therefore in 2002 the former Ministry of Social Affairs, supported by UNICEF and Handicap International created a reform group, charged with the task of assessing the functioning of the Commissions and making some recommendations on a new mandate and new procedures for the Commissions.

A structured reform

The project was divided into several stages, including:

- A survey on how many children have been categorised and how the process of categorisation worked,
- National and international consultation,
- Drafting of a new act,
- Creation of tools of assessment and of guidelines for professionals,
- Creation of regional teams for the dissemination of the new model and training on tools for implementation.

Through all these different steps a consultative and participative approach was enforced, involving the representatives of three ministries:

- Ministry of Social Affairs (former), who initiated the group,
- Ministry of Education (former), under whose jurisdiction it falls,
- Ministry of Health, as the commissions are usually based in health centres.

People with disabilities were consulted throughout the process either through public debates at the local level or by being directly involved in the group.

The categorisation process

Composed of a multidisciplinary team the commissions gave technical advice on the type and impairment of the child, as well as a recommendation of the type of schooling he/she should attend.

The survey showed that:

- A sizable number of children are categorised as intellectually disabled and directed to separate special schools although the cause of their intellectual developmental difficulties is a high level of social and educational neglect (particularly amongst Roma children),
- For many children the placement in institutions is recommended although these children could stay with their families on the condition that appropriate community support is provided,
- Categorisation is often influenced by the existing system of institutions for these children, and not by their needs,
- Many children come to the attention of the Commission too late, usually at the age of school enrolment (age 7) and thus the precious time for early intervention is lost,
- Follow-up of categorised children and assessment of the effects of the measures undertaken is not done on a regular basis,
- The documentation of categorised children is not adequate and does not facilitate the planning of care for children with disabilities at the community level,
- Though sometimes present, neither the child nor his /her legal representatives are consulted for the decision.

On the basis of these observations some recommendations were proposed. The scope of the changes to be made was a delicate question. In a context where the medical model was predominant and commissions were the key point for families of children with disabilities the challenge was to bring in changes that would radically change the approach without altering the system and putting families and professionals under stress. The options were either a "light" reform, acting only on the functioning of the commissions, without changing the underlying model, or changing this model to bring about deep changes.

A new model, the Disability Creation Process

Through national and international consultation the reform group was able to decide on the more ambitious of the two alternatives, to change the underlying model for assessment. Exploring the alternative models of classification to replace the very medical one that was enforced until then (classification according to the level of impairment), the reform group encountered the DCP.

This holistic model gained the approval both of professionals and people with disabilities for several reasons:

- The DCP brought together the medical diagnosis and the capacities of the person with which professionals, and more specifically defectologists, were used to working. The DCP also introduced the environment and life habits of the person, which allowed families to express their expectations and wishes,
- It was a practical model that, with appropriate training could immediately be translated into tools accessible to most professionals,
- The model recognises the specificity of each professional member of the commissions and provides them with a common language in order to work with a true interdisciplinary approach.

Through this model the question of the purpose of categorisation is definitely addressed. The Commission's only purpose is assessment and orientation. The Commission now directs the child and their parents towards the appropriate services in the education, rehabilitation and health areas. Within the reform of the Commission, the name therefore has changed to the **Commission for the Assessment of Needs and Orientation of Children with Disabilities**. The Commission becomes one of the stakeholders at the local community level of the social integration of the child and of support to the family.

Structural changes

The change in approach was accompanied by changes to the organisation of the commissions. Commissions become professional bodies with one permanent member that will ensure the follow up of procedures and facilitates information flow between members:

- They intervene much earlier in the life of the child, as soon as the impairment is noticed,
- The distinct steps of the process have been clarified. Four stages can be distinguished:
 - Assessment of the Disability Creation Process,
 - Assessment of the needs of the child and the family,
 - Elaboration of individual plans,
 - Follow up of the plan's implementation,
- For each step the professional involvement has been specified,
- They include the opinion of the child and his/her parents,
- Commissions have an obligation to follow up on the child and the implementation of their recommendation; the process is no longer one-off,
- Commissions have the duty to keep a register of the children that come before them.

Through these main changes the reform group has realised the wishes of most stakeholders previously involved in the categorisation process, by having a procedure closer to the person and more adapted to its needs.

Next steps and obstacles for going forward

The act, under the jurisdiction of the former Ministry of Education has been awaiting incorporation into bylaws for over one year. This delay has slowed down the process of change. Toolkits are ready and ten regional teams have been sensitised to the new model and mandate of the Commissions. As soon as the act is integrated in the legal corpus, training of Commissions' members should start through the support of the ten regional teams. Since the act was presented to the former Ministry, the government has changed and the new administration has slowed down the process of reform.

Life story 5: The impact of the Commissions for Categorisation, from Bosnia and Herzegovina

My name is Mato. I was born in 1953 and lived in a typical rural setting in Zivinice, a small town near Tuzla, Bosnia. My father was a military officer and my mother was a housewife. I received no formal education while I was of school age. I was 25 years old when I first started my education.

When my parents divorced neither parent wanted to take care of me so I grew up with my grandmother in her village. I was four or five years old when I first realised that I was different than other children. I realised I couldn't run and play like the other children. I had cerebral palsy. Although I had no problems with the local children, their parents told them to avoid playing with me because of my disability. I turned to learning as a way of compensating for my inability to participate in all activities with my friends.

When the time came to enrol in school I was sent before a Commission for Categorisation of Children with Developmental Difficulties in Tuzla. Several doctors and defectologists for disability assessed me as having cerebral palsy and an intellectual disability. This meant that I couldn't attend school. No one questioned the Commission's findings because it was considered fully competent and incapable of errors. The Commission also found that my disability was of a permanent nature and that no medical reviews of my condition were necessary. I was therefore denied access to formal schooling by the Commission. This decision was made in writing and it had a profound effect on the rest of my life.

From the ages of seven to ten I taught myself to read and the basics of mathematics. I read a lot of poetry. Due to the effects of cerebral palsy I was unable to hold a pen and write, which made learning very difficult. All the studies I did were spontaneous, without an organised curriculum. When I was fifteen I devoted myself totally to reading and read any book I could get my hands on. I was offered informal schooling at the local rural school but I quickly outgrew the situation.

As a twenty year old, I saw my generation leaving the village to further their education, marry or perform their military service. I too was interested in obtaining an education. My uncle decided to take me to the Centre for Social Work to see if they could help me.

Without any psychological or other assessment, the Centre sent me to the Institute for Mentally Retarded Children in Pazaric, a town far from my home village. Luckily, the staff at the Institute sympathised with my predicament and sent me to Sarajevo for correction of my diagnosis. It was found that I actually had an I.Q. of 111+ and did not have an intellectual disability. The psychologist who tested me, however, could not correct the papers I had from the Commission for Categorisation. So the formal diagnosis remained. From Sarajevo, I was sent to the Rehabilitation Spa at Fojnica.

It was as if a new, positive window on the world had opened for me there. I realised that this was the start of a new life for me and that there was no going back. I found many new friends there and met many people with disabilities. There was a school at the spa and I decided to ask the staff whether a person who was physically unable to hold a pen had the right to attend school and sit for examinations. The director of the spa, who was a very open minded person, said that he could find no legal barriers for me to receive an education and that it was up to the individual, me to decide.

I threw myself at the task at hand and completed 6 grades of education in 6 months. The time came when I was told that the Rehabilitation Spa could no longer afford to accommodate me. I refused to go back to the village and instead lodged with two families in Zivinice. While there I met a woman who helped put me in touch with education professionals. They arranged for me to attend evening classes. With no particular adaptation of facilities or marking concessions for my disability, I managed to complete years 7 and 8. After completing primary education I realised that I had become urbanised and couldn't go back to living in the village. I spent many years moving from institution to institution with no real therapy or treatment. No one wanted to correct my diagnosis even though it was obvious that it was incorrect. In 1982 I went to Titograd (Podgorica) in Montenegro to The Institute for Professional Rehabilitation and Training of Invalids. I successfully completed my high school diploma. I stayed on in Podgorica for one more year and completed a clerical administration diploma as well.

At one stage, before I had enrolled in high school in Podgorica I had an offer for the effects of my cerebral palsy to be reduced by surgery. I accepted the offer, as I had always hoped that a professional competent to change the commission for categorisation's findings would see me differently and I saw this as an opportunity to present my case. I went to the public hospital in Zvezdara, Belgrade for examination. They decided not to operate as I was sufficiently adapted and instead referred me to the Institute for Cerebral Palsy. The institute only offered primary education, which I had by then completed, so they couldn't help me to complete my high school education degree. I stayed in touch with them and this link with the institutions in Belgrade led to the diagnosis of 'mental retardation' finally being formally corrected. It happened when I was 28 years old after many years of struggle and once I had completed my education but I now have proof in writing of the errors that were made.

The situation regarding quality standards, licensing and accreditation in South East Europe

In all of the countries in the region, alternative support services have emerged parallel to the former system of state financed and controlled institutional services. These new initiatives, mainly within civil society, have evolved, many of them providing credible alternatives to institutional care with well-trained professionals and a high involvement of users and families. Still, there is a lack of, and in some countries even absence, of clear processes of accreditation, licensing and quality standards, and it is evident that the state does not take enough financial and technical responsibility in the development and running of services. The state owned institutions have better financial coverage, but not any clear obligations to follow standards or to ensure the quality of care. It is also difficult to see how the money from the state is spent since there is lack of transparency among the institutions and often a conflict of interest.

Initiatives for change

Implementing quality standards is just beginning to occur, especially in countries closest to EU accession. The best example is Romania where one of the main achievements of social services reform has been the creation of standards adopted and enforced by the government¹⁰¹. This process began approximately 3-4 years ago due to the professional work of NGOs and their methodological documentation of service provision. Subsequently, NGOs were the main engine of change in all standards of the care system. As NGOs in Romania evolved, they took a methodological approach to standards and quality of services within social service reform. EU accession pressure stepped up the reform of social services and international actors such as UNICEF, the World Bank, USAID, and the EU were able to push the government to address the issue of standards within the care system.

As a result of NGO, EU and international pressure to adopt new standards, **Aurora Day Care centre** was asked by the government to write a first draft of standards for Day Care centres because of their innovative work as a service provider. Parallel to this, other organisations and institutions were asked to write standards for their services. The Ministry made a general frame for standards in which all the different standards were rewritten to fit so that they could be applied to all social services including those regarding people with disabilities such as foster families and residential homes. After the government had established these standards, they adopted new legislation for service providers complying with minimum standards to be able to receive public funds. However, the process of licensing and accreditation,

has not yet begun in Romania¹⁰². The main concern for Aurora is that there is no culture of quality standards in Romania, and no methodology for conducting proper evaluations and assessments of services, and there is as well a lack of a complaint system for the users / clients.

In Romania, EU accession pressure to implement standards has been largely focused on improving economic and industrial conditions in the country under the ISO systems for the standardisation of enterprises and quality services. The EU did not provide a guide comparable to the ISO for implementing social service standards. At the same time, pressure from the EU to reform social services and close institutions in order to accelerate the accession process has had a two-fold result. In one sense, it has forced the Romanian government to consider social protection reform as a part of their objective for gaining access to the EU¹⁰³. On the other hand, the intense pressure from the EU to reform services was not accompanied by a comprehensive strategy for providing technical support and training to caregivers on the process of transformation. As a result, their capacity to adapt to the new social services changes has been hampered both by the rapid speed of the reform process and the lack of proper training and information¹⁰⁴.

The aim of quality standards is to ensure that social care is aimed at supporting people to participate and contribute in society rather than just "keep them going"¹⁰⁵. Measures such as improving standards and systematic reviews help to ensure that service provision is based on these objectives.

Looking ahead

- **Training on quality standards and needs-based assessments using tools such as the ICF, Disability Creation Process and inspired by the UN Standard Rules,**
- **Develop pilot projects for implementation of standards,**
- **Establish a legislative framework for quality standards, accreditation and licensing,**
- **Create regulatory bodies for monitoring and implementation such as a Professional Council, an Accreditation Council, and an Ombudsman,**
- **Develop standards and codes that embrace the holistic approach to disability**
- **Develop data systems on quality of standards¹⁰⁶,**
- **Develop professional conduct and ethic codes.**

The process of standardisation should be completed in partnership with local NGOs, DPOs, and people with disabilities, their families and community members.

¹⁰¹ Aurora Day Centre, the Romanian National Authority for Child Protection and Adoptions and UNICEF, "Quality Technical Standards of Day-Care Centres for the Disabled Children in Romania," report (Bucharest: UNICEF, 2002): 2.

¹⁰² Diana Chiriacescu, director of Aurora Day Centre, Bucharest, Romania, interview conducted in Belgrade, June 2004.

¹⁰³ Aurora Day Centre, the Romanian National Authority for Child Protection and Adoptions and UNICEF, *ibid*, 7-8.

¹⁰⁴ Diana Chiriacescu, director of Aurora Day Centre, Bucharest, Romania, interview conducted in Belgrade, June 2004.

¹⁰⁵ Kathryn Ellis, *ibid*, 3.

¹⁰⁶ Bilson and Harwin, *ibid*, ix.

BOX 33**New bill on insurance and disability pension in Serbia adopted in 2003 by parliament**

The new bill adopted in 2003 regulates pension and disability insurance in Serbia. The bill defines the right to disability pension for insured workers who lose their ability to work completely due to changes in their health condition due to an injury caused in the workplace. Disability is defined as a complete loss of ability to work or an ailment that cannot be cured by rehabilitation (article 21). Therefore, an insured person acquires the right to disability pension when the disability is caused by an injury at the workplace or an ailment that occurs due to the work environment. The bill includes a provision on family pension if a child within the household has a disability. The family has the right to this pension even after employment or independent work is completed.

The main aspects of this bill include:

- Disability pension is available only for people who acquire a disability at the work place,
- In order to receive disability pension, the level of disability has to be 100% (except in certain specific cases defined in the bill),
- Establishing eligibility for disability pension is based on the findings of a team of experts.

Why this bill is problematic:

- Under this bill, disability pension does not cover people who are born with a disability but offers compensation only for those who acquire one at the workplace,
- The bill reflects an overprotective medical approach to disability,
- There is no provision in the bill for people who are not 100% disabled but have a disability that limits their ability to work,
- There is no compensation for assistance or help from another person
- There are no measures in the bill for professional rehabilitation or employment training for someone who has or acquires a disability.

Establishing the existence of disability is based on an evaluation performed by court experts. The bill does not define the type of experts that make up this group. This bill does not regulate compensation for personal assistance or another's help and care. Instead, beneficiaries realise their right to compensation for assistance from the former regulations that were in power at the time this bill was adopted. Compensation for assistance from another person will not be changed until a new bill is adopted in social protection.

Source: Damjan Tatic, "Legislation News," Bulletin of the Association of Students with Disabilities, no. 8, (Belgrade: Association of Disabled Students of Serbia, November, 2003): 10-11.

However, it is the state's responsibility to implement, coordinate and plan for quality provision of service on the community level. As shown in spotlight 8, the Day Care centre in Bijelo Polje, Montenegro, is an interesting example of different stakeholders working in partnership to establish a Day Care centre based on the holistic model of disability.

4.3 The need for disability pension reform

As states in the region transform their economies, they are facing the need to adapt their pension systems. Paradoxically, the generosity and comprehensiveness of the inherited safety net of the socialist regimes makes the gap between pre and post-conflict systems unusually large¹⁰⁷. As a result of shrinking contribution bases and the inability to finance the former pension systems unusually large. As a result of shrinking

contribution bases and the inability to finance the former pension systems, populations in receipt of pensions are not protected from poverty¹⁰⁸. However, to avoid bankruptcy, transition in many cases involves reforming the eligibility criteria for disability pension¹⁰⁹ which could have a negative impact on the livelihood of people with disabilities. There was and still is no proper income maintenance system in operation in the region for people with disabilities. Therefore, disability pension is one of the only sources of income for people who cannot work due to a disability. Disability pension under the former system was based on benefits according to categories of disability such as war veterans or according to the type of disability one had; benefits were not based on one's real needs.

Moreover, the system was built in such a way that it acts as a disincentive for inclusion in the workforce. Once one gets the right to disability pension, there

¹⁰⁷ Christian Bodewig et al., Draft Article "Social Protection in Post-Conflict Environments in ECA," Spectrum Magazine (Washington, D.C.: World Bank Publication, 2003): 1.

¹⁰⁸ David Lindeman, Michal Rutkowski, and Oleksiy Sluchynskyy, "The Evolution of the Pension Systems in Eastern Europe and Central Asia: Opportunities, Constraints, Dilemmas and Emerging Best Practices," (Washington, D.C.: World Bank, 2003): 2-3.

¹⁰⁹ Jean-Noel Martineau, "The National Pension System of Serbia: Preliminary Fiscal Analysis - Draft," (Belgrade: USAID - Bearing Point, 2004): 21-27.

is no flexibility to allow for a safe reintegration into the labour force. However, considering that the labour environment in South East Europe is virtually inaccessible for people with disabilities regardless of the type and severity of their disability and even if disability pension is not a real support for inclusion, there is a need for preserving it while proper and effective income maintenance systems are created. An intermediate disability pension should be based on an individual's needs not on categories of disabilities to optimise its impact on social participation of beneficiaries.

Initiatives for change

Many states have placed an emphasis on disability pension reform as a way of redirecting resources. Furthermore, influential agencies such as the World Bank, stress the notion of reforming the pension and insurance schemes as a priority for states within social development programmes (Box 33).

For many countries in the region, pension deficits are extremely high due to the collapse of the former social welfare system and the process of decentralisation. As a result, governments in South East Europe are adopting new disability and pension benefits with strict eligibility criteria in order to redirect public finances and curb the pension deficit¹¹⁰. In 2003, the Serbian government adopted a bill tightening eligibility criteria for disability pension.

These reform initiatives consist of not only tightening eligibility criteria but in most cases they are drafted without comprehensive needs-based assessment

mechanisms and without specific measures for professional rehabilitation and employment inclusion.

Looking ahead

Governments need to redefine the financial incentive to use residential care mainly because the current funding streams create an incentive for local governments to rely on institutional care as higher levels of government fund them. The fiscal system needs to shift to a client-based focus as Tobis suggests, where "money follows the client" meaning that local authorities are granted one allocation from the national budget to be used either for social services or residential care on a per client basis. Because community-based services are argued to be less expensive, this approach will create an incentive for community care¹¹¹. However, this strictly fiscal argument for redirecting resources can be a slippery one as the number of beneficiaries would probably increase in a community-based service system, possibly making it more costly than residential institutional care. Since there is limited research on the cost of disability it is hard to speculate either way. However, an evaluation and monitoring system can be established that will follow pilot projects and community-based service reforms in order to prove that the quality of life of a person with disabilities improves with more choices, access to society and more opportunities to participate. It might as well reduce the reliance on social welfare if persons with disabilities have the opportunity to contribute in the community.

BOX 34

Pension reform initiatives

Pension reform in Serbia and Montenegro has largely been in the form of reformulating the parameters of the Serbian Pension system, PAYGO, and this has included tightening the eligibility criteria for disability pension. Within the reform rounds, benefit rules for disability were tightened so that a person with disabilities can only receive pension if they are 100% incapable of working.

Source: World Bank, Serbia and Montenegro: Recent Progress on Structural Reforms, November 2003, pg. 20-22

In Bosnia and Herzegovina, in cooperation with the World Bank, the preparations have started for the reform of the pension system through the Social Insurance Technical Assistance Project (SITAP). The purpose of this project is to strengthen the effectiveness and efficiency of the health care and pension insurance system for future reforms of social insurance. The purpose of insurance schemes is to allow people with disabilities to be given the rights to manage their resources and benefits. In addition, the project will support the competent ministries to build capacities in defining the strategic goals, business and financial planning and effective implementation of the adopted reforms. The SITAP also calls for a state level disability pension fund to be created. The purpose of insurance schemes is to allow people with disabilities to be given the rights to manage their resources and benefits. Within pension reform, the SITAP sets out a unified pension system for Disabled War Veterans including calls for building tools and instruments to encourage the employment of veterans with disabilities.

Source: Poverty Reduction Strategy Paper for Bosnia Herzegovina 2003, pg. 166-169.

¹¹⁰ Interview with Bearing Point, Belgrade, 2004.

¹¹¹ Tobis, *ibid*, 54.

5. MOVING FORWARD: THE NEED FOR A NATIONAL DISABILITY STRATEGY AND NATIONAL COUNCIL ON DISABILITY

UN Standard Rule 14. Policy Making and Planning (extracts)

States will ensure that disability aspects are included in all relevant policy-making and national planning.

- States should initiate and plan adequate policies for persons with disabilities at the national level, and stimulate and support action at regional and local levels,
- States should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status,
- The needs and concerns of persons with disabilities should be incorporated into general development plans and not be treated separately.

A National Disability Strategy is a cross-sectoral policy-planning tool with comprehensive long-term objectives for building an enabling system underpinned by full participation. It should accompany the decentralisation process and is important because it has the potential to make comprehensive changes both in the legal framework and in practice, which is particularly important because of the transitional position of the care system in the region. It is also important to build and empower a National Disability Council to contribute to the planning of a National Disability Strategy and monitor its implementation.

5.1 Key step: developing and implementing a National Disability Strategy and establishing a National Council on Disability

- A National Disability Strategy should be based on the new disability paradigm using international standards,
- The plan or strategy should be reflective of different trends in the disability movement,
- A National Council on Disability should head this and monitor the implementation.

BOX 35

The characteristics of a good disability policy plan outlined by Agenda 22 Local Authorities: Disability Policy Planning Instructions for Local Authorities

Begin with using the UN Standard Rules as the underlying guideline for the plan while applying the concept of equal partnership with DPOs and people with disabilities in the development and implementation of the plan.

The steps include:

- Long-term overarching objectives such as, "In our state, all citizens shall be able to participate in cultural life on equal terms".
- A summary of inventories indicating how the different social service activities in different regions or municipalities work in relation to the UN Standard Rules,
- A summary of the social service needs of people with disabilities, critical information such as a general description of the total national service needs of people with disabilities disaggregated by municipality,
- Long-term time table indicating the fields in which measures need to be taken and how these measures are to be spread out over a specified year,
- Objectives and concrete measures - description of targets and measures for each field to be addressed within the period of the plan. The measures should be clarified in such a way as to indicate the steps to be taken, when they are to be completed, the agencies responsible for their implementation and how they are to be funded,
- Evaluation and revision - procedures as to when and how the plan is to be evaluated and revised.

Full text of Agenda 22 is available in the annex to this report.

Ensuring a change in paradigm means that the state mainstreams disability into all sectors, particularly when planning and developing policies so that disability policy measures are always taken into account from the beginning of all planning¹¹². A National Disability Strategy should be monitored and implemented by a National Council on Disability which should have the following characteristics:

- It should be inter-ministerial,
- It must include people with disabilities, their representatives and other civil society members such as human rights organisations and professionals working in public services,
- It should be representative of the different trends in the disability movement,
- The Council must be effective in allowing for consultation with people with disabilities.

While it is important that a National Disability Strategy includes people with disabilities and organisations of people with disabilities, this is a state responsibility and a critical stake for the overall social development. Finally, policies with broad principles but without concrete mechanisms for the allocation of resources have little chance of achieving a sustainable change.

An example of good policy-making for a national disability strategy of action is outlined below in Agenda 22, a disability policy planning tool kit based on the UN Standard Rules¹¹³.

5.2 Initiatives for change

In Albania, following the collapse of the socialist system, residential institutions were in dire condition. The state of their near collapse provoked international actors, namely the European Disability Forum and the Council of Europe to push for reform of institutions putting pressure on the government to make changes. This prompted the Ministry of Labour and Social Affairs to ask that a strategy for people with disabilities be drafted using the UN Standard Rules in 2003. The Ministry of Labour and Social Affairs called for the creation of an inter-ministerial committee on disability with appointed experts from various line ministries to work with DPOs to draft a strategy and action plans. The strategy takes an inter-ministerial approach meaning that the Ministry of Health, Ministry of Labour and Social Affairs and the Ministry of Education own different parts of the strategy. While this initiative is important because it uses the UN Standard Rules and is being planned in collaboration with local DPOs, current comprehensive information on the situation for people with disabilities in Albania is missing from the overall planning and implementation process.

Croatia has adopted a National Disability Strategy called the *National Strategy on a United Policy for People with Disabilities* produced by the state Institute

for the Protection of Families, Motherhood and Youth to be enacted from 2002 to 2006. The planning for the strategy began in 1995 and was adopted finally in 2001. The plan calls for a special office to be created within the government that deals specifically with disability as well as the establishment of an Ombudsman for people with disabilities. The strategy is to be implemented by all ministries and the state Institute for the Protection of Families, Motherhood and Youth will monitor the implementation of the strategy and report to the Federal Government once a year. The government then reports these findings to the National Parliament¹¹⁴.

The National Disability Strategy in Croatia targets the following areas making the relevant line ministries responsible for implementing the strategy in each field:

- Family and civil society,
- Health, sports and recreation,
- Education,
- Professional rehabilitation, employment and work,
- Housing, mobility and accessibility,
- Pension plan (retirement),
- Social services and welfare,
- Coordination and information.

There are examples in the region of various types of councils on disability. In Serbia, a **Government Council on Disability** was established in 2002 to monitor the reform process regarding disability policy. At that time, the Government Council on Disability was made up of 9 ministries, 12 DPOs, the Serbian Red Cross, and the Faculty of Defectology. The 12 DPOs on the Council included, among others, the unions representing specific disabilities such as Union of the Blind and Visually Impaired, and the Union of the Deaf and Hearing Impaired, the Association of Students with Disabilities Serbia and the Centre for Independent Living Serbia. The Council was at the level of the Government (meaning above the ministries) chaired by one of the Deputy Prime Ministers and the former Ministry of Social Affairs was the official secretary of this body. The Council worked with varying degrees of success but by the end of 2003, the Council's progress was stifled due to a lack of cooperation between the various DPOs as well as a lack of coordination between the various ministries. The change of government in Serbia in spring 2004 brought the change to the Government Council on Disability. The new government started all over again, and established a new Government Council on Disability, in September 2004, with a different composition, management structure and with less political influence. The Council now has fewer representatives from DPOs (7 in total) and is now chaired by the Deputy Minister of Labour, Employment and Social Policy.

¹¹² The Swedish Co-operative Body of Organisations of Disabled People, Agenda 22: Disability Policy Planning Instructions for Local Authorities, revised version (Modintryck: Stockholm, 2001): 17.

¹¹³ The Swedish Co-operative Body of Organisations of Disabled People, Agenda 22: Disability Policy Planning Instructions for Local Authorities, revised version (Modintryck: Stockholm, 2001).

¹¹⁴ Državni Zavod za Zaštitu Obitelji, Materinstva i Mladeži, Nacionalna Strategija Jeinstvene Politike za Osobe s Invaliditetom od 2002 do 2006 godine, Zagreb, 2002 : 18.

5.3 Looking ahead

A National Disability Strategy should incorporate policy planning across all sectors of the care system re-shaping care system governance to facilitate social participation and empowerment of people with disabilities. The plan should come from lessons learned during pilot projects and from comprehensive assessments of the situation for people with disabilities and should be designed to best address the community's needs. It should include legislation that authorises and funds

local authorities to provide a range of services specific to their jurisdiction. National Disability Strategies should be a tool to guarantee the mainstreaming of disability in PRSP implementation as well as the EU accession process. Ideally, an inter-ministerial working group with the assistance of DPOs, NGOs and with the guidance of international agencies should lead the development of a National Disability Strategy¹¹⁵. As Joseph Stiglitz argues, a broadly participative process promotes truly sustainable and successful long-term development¹¹⁶.

¹¹⁵ Tobis, pg. 53.

¹¹⁶ Joseph E. Stiglitz, "Participation and Development: Perspectives from the Comprehensive Development Paradigm," *Review of Development Economics*, Blackwell 6(2) (2002): 163-82.

Life story 6: The fight to achieve one's dreams, from Macedonia

Milena from Macedonia

At the age of eighteen, I was in a car accident in Croatia. Since then, I became a wheelchair user. It was a big challenge for me. I was traumatised by the thought of having to live the rest of my life in a wheelchair. The medical staff in Zagreb changed my mind. They taught me how to accept my new life and convinced me that I could still achieve my dreams.

When I came back to Macedonia, the situation was slightly different. Nobody had seen a person in a wheelchair before. My parents did not let me go out. They were ashamed of me.

I decided to get my own apartment. There were new buildings equipped with a ramp. Unfortunately the existing ramps were not adapted for people with disabilities. The building company agreed to rebuild a new ramp for my building. They also gave me a ground floor flat and allocated a car park specifically for my car.

All my neighbours are now very supportive. All kids and young people are always very enthusiastic to give me hand. Of course, you sometimes meet some negative people such as the ones who blocked my car park with heavy flowerpots.

I always tried to make my dreams come true. I crossed Europe with my wheelchair, hitchhiking from one place to another. I learned a lot and really enjoyed discovering so many countries and people. I then received a gold medal for my performance in the Yugoslav national team in athletics. I like my new activity: I am now volunteering for the Macedonian organisation Polio Plus. I would like to speak in conferences to describe the life of women with disabilities in my country.

I really enjoy my life!

CONCLUSION

During 12 years of activities in South East Europe, Handicap International has been supporting people with disabilities, care system professionals both in residential institutions and in community-based services, as well as policy-makers in their effort to improve the living conditions of people with disabilities. As shown in this report, Handicap International is witness to numerous valuable initiatives throughout the region that are currently struggling to survive. Both the lack of political will and comprehensive policies in the region in addition to a global misunderstanding of disability issues undermine the change process towards an enabling system aimed at an equalisation of opportunities and full participation of people with disabilities.

Policy-makers and decision-makers, as well as most professionals, are trapped in a medical approach to disability and thus in an institutionalised way of providing services. Operating a shift of paradigm involving and supporting civil society would save time and resources in the long run while having a very positive impact on the lives of people with disabilities.

As the biggest barrier for change is a common misperception of disability, the states have to make significant steps immediately in order to initiate the change:

- Adoption and enforcement of strong anti-discrimination and comprehensive disability-related legal frameworks,
- Raising awareness and proliferation of proper and relevant information related to disability and people with disabilities,
- Guaranteeing that new buildings, construction and public transportation, communication and technology are accessible and progressively remove existing barriers,
- Ensuring that new generations of health, social welfare, and education professionals are aware and trained on the new disability paradigm and that professionals in ordinary services are sensitised as well,

- Mainstreaming of disability into ordinary services such as (re)habilitation in Primary Health Care or social welfare,
- Generalisation of inclusive education as it will bring a change in the perception of disability for the future generations besides empowering people with disabilities,
- Reforming the definition of disability that influences all health care and social protection systems so that individual's needs and choices are taken into consideration,
- Supporting community-based services through proper licensing, accreditation and public funding schemes processes along with the implementation of quality standards in services.

Considering the changes that should happen, the apparent shortage of resources and the unknown cost of measures to be undertaken seem to be a strong disincentive for the state to develop proper policies that foster the new disability paradigm. Yet, this question of the cost of disability is mainly an issue for people with disabilities and their families who are struggling with exclusion and poverty.

The limitation of resources cannot be an alibi for the status quo or uneven reforms. It should be a strong motivation for governments to build true partnerships with organisations of people with disabilities for the development of consistent National Disability Strategies that will allow for relevant prioritisations.

Considering the current favourable political momentum for reform and after years of crises that have endangered the rights and dignity of people with disabilities, the time for change has come.

Building an enabling system, promoting the equalisation of opportunities and removing barriers to participation of people with disabilities is becoming an acknowledged duty for the states, notably through the current elaboration of the UN international convention for the enjoyment of human rights by people with disabilities. Nowadays, the main question for states and other stakeholders involved should not be about fulfilling this duty or not, but how to move forward.



LEGISLATIVE OVERVIEW



LEGISLATIVE OVERVIEW

COUNTRY DISABILITY LEGISLATIVE OVERVIEW

ALBANIA

GENERAL FACTS ABOUT ALBANIA

People¹

Population (July 2004)	3,544,808
Population growth rate (2004)	0.51%

Government²

Country name	Republic of Albania
Capital	Tirana
Constitution	Adopted by referendum on 28 November 1998

Economy³

GDP (2003)	purchasing power parity - \$16.13 billion
GDP real growth rate (2003)	7%
GDP - per capita (2003)	purchasing power parity - \$4,500
Unemployment rate (2003)	15.8% officially; may be as high as 30%
Population below the poverty line (2001)	30%

Health⁴

Total health expenditure per capita (Intl \$, 2001):	150
Total health expenditure as % of GDP (2001):	3.7

GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES

The Albanian Constitution (article 1/f) stipulates that the state and the government must act in favour of people with disabilities in the field of medical rehabilitation, special education, social integration and improvement of living conditions. In Albanian legislation people with disabilities are classified according to the type of disability: sensory disability (people with hearing or visual impairment), physical disability (people with paraplegia, workers with disabilities, and war veterans with disabilities), and intellectual disability (people with intellectual disabilities or mental illness). These definitions are based on specific laws issued to define the status of people with disabilities: *Law on the Status of Persons with Visual Impairments*, *Law on the Status of Persons with Paraplegia*, *Law on the Status of Disabled Workers*, *Law on the Status of Disabled War Veterans*, *Law on Mental Health*. A National Strategy for people with disabilities in Albania is currently in the process of adoption.

SOCIAL WELFARE

a) **Main legal documents** - The main Law in the field of social protection of economically vulnerable groups is Law No. 7710 "On Financial Assistance and Social Care", written in 1993. It defines the system of social welfare

¹ CIA - The World Fact Book - Albania, available at: www.cia.gov

² Ibid

³ Ibid

⁴ World Health Organization, available at: www.who.int

and provision of financial assistance to the families without means for living. The institution called State Social Service (SSS) directs the social assistance program.

b) **Beneficiaries** - Article 5 of the Law states that financial assistance can be given to families having one or more members with disabilities have a visual impairment, intellectual disabilities, severe difficulties in development or when members with disabilities need support and care from another person.

c) **Rights** - Financial assistance ensures financial benefits for families whose living conditions are below the poverty line and who have a family member with disabilities. The municipal council sets the period one will receive benefits based on a report provided by the Medical Commission. Families that have a member with disabilities placed in a social residential institution do not enjoy this right. Financial assistance is given at first in cash for a period of one month. If after one month the living conditions are not improved, the financial assistance continues. The law on financial assistance and social care regulates as well the placement of people with disabilities into residential institutions. These types of institutions are funded out of the state budget.

Benefits according to specific laws

Considering the status of people with disabilities, Albania has a specific legal system since there are laws regulating a person with disabilities according to different categories of impairment:

Persons with visual impairments, according to the specific law, *Law No. 8098 "On the Status of Blind People"*, defines this category of disability as people who have complete or partial visual impairments who cannot work under regular conditions. The rights of people with visual impairments include: tax-exemption (except when a person is operating a private business); tax-exemption for employers who hire people with visual impairments; free education; financial assistance during secondary and tertiary education and during vocational training; health insurance (including the medication and orthopedic devices at a 50% discount). Monthly financial benefits for people with visual impairments are 70% of the national minimum wage, plus other financial benefits. The same benefit is given to the caregiver.

Persons with mental health problems are regulated by *Law No. 8092 "On Mental Health"* which stipulates that people with intellectual disabilities should have free access to health services, education, and rehabilitation. If they are under the age of 18 and accommodated in private institutions, the state should cover the expenses. People with mental illness and his/her guardian have the right to information on the health conditions and methods of examination and therapy.

Persons with paraplegia and tetraplegia are regulated by the specific law, *Law No. 8626 "On the status of Persons with Paraplegia and Tetraplegia"* which stipulates that the state creates the conditions for persons with paraplegia to participate in social life like other citizens, providing them with a sufficient financial support to allow living in dignity including, shelter, proper work, and sporting activities. They are direct-tax-exempted. The State promotes university education of persons with paraplegia. The State covers health insurance including the costs of medication. Those who are immobile can benefit from home service. Urban transport is free; inter-urban transport is half-price. The State provides financial credits for accommodation to people with paraplegia.

Disability payment for students with disabilities attending university

The Decree of Council of Ministers, Law No. 311 "On Disability Payment⁵", declared on 11 July 1994, stipulates that people born with a disability receive a disability payment to the age of 21 or until the age of 24 if attending university. The amount of the payment is 70% of the minimum wage. Since these specific laws do not cover all categories of disability, the status of people with hearing impairments is not included in this special regulation.

d) **Financing** - Both central and local governments carry out the management scheme. The state Social Service collates figures on the level of poverty for each administrative unit (including municipalities and communes), but the local government distributes the money. The budget is prepared entirely by the Ministry of Finance. The law allows the local government some freedom to use the income gathered from local taxes but this has not been implemented yet.

HEALTH CARE AND INSURANCE

a) **Main legal documents** - In compliance with the Constitution several laws are enforced to ensure the right to health care such as *Law No. 6227 "On Health Services and Free Health Care"* amended in 1983⁶. The Ministry of Health is responsible for national health policy, control and coordination, analysis and evaluation of medical outcomes, national financial and human resource planning.

b) **Rights** - Based on the *Law on Social Insurance*, all social insurance scheme contributors are covered in case of accident or injury. The orthopedic devices are partially covered by the scheme, and partially by the state. Like all other citizens, people with disabilities are contributors to the health and social insurance scheme.

c) **Financing** - Albanian health services are funded through a mix of taxation and statutory insurance. The bulk of funding still comes from the state budget, but the tax base is problematic due to low incomes, the large

⁵ This Decree of Council Ministers is based on Law No. 7710, from 1993 "On Economic Aid and Social Care" amended under another Decree of Council Ministers called Law No. 457 in 1995.

⁶ This law was amended from Law No. 3766, in December 1963, and changed later by Decree No. 4875 in 23 September 1971 and most recently by Law No. 6227 (in 29 January 1983).

informal economy and problems with tax collection⁷. Based on *Law No. 7870*, from 13 October 1994, "*On Health Insurance*", health care is financed through compulsory health insurance, the state, direct payment of citizens, voluntary health insurance and external sources of funding (such as foreign aid).

PENSION AND DISABILITY INSURANCE

a) **Main legal documents** - *Law No. 7703 "On Social Insurance"* regulates the pension and disability insurance system in Albania. Compulsory insurance can be accessed in case of disability, physical injury, work accident and occupational illness, or in case of accident outside of the workplace or because of illness.

b) **Rights** - Persons can realise rights from social insurance only if they have been contributing to the social insurance scheme. Persons who become partially or completely disabled may be eligible for disability pension. Compensations for a work accident or occupational illness cover medical treatment and rehabilitation. Insured persons who had a work accident or suffer from an occupational illness have the right to additional compensation or vocational training. Persons who become disabled because of a work accident or an occupational disease will benefit from an allowance for the following conditions: for temporary disability, for permanent disability or for partial disability.

People with disabilities between 21 and 24 years of age, who were employed, but became disabled at work are covered by the Social Insurance Service as insurance scheme contributors. They thus receive the disability pension. Those who became disabled after the age of 24 but never worked, have a specific status such as people with paraplegia and people with visual impairments. Those who do not fit in any status regulated by law (such as persons with hearing impairments) if they become disabled after the age of 21 are not considered eligible to be beneficiaries of the disability payment.

c) **Assessment** - Commissions for assessment are called Medical Commissions for Assessment of Working Capacity. The commissions make assessments of a person's working capacity and the need for care and assistance of another person⁸. Commissions are under the jurisdiction of the Ministry of Health and Ministry of Labour and Social Affairs. The commission consists of medical specialists and doctors from the Social Insurance Institute which is under the Ministry of Labour and Social Affairs. The assessment is based on the medical report provided by specialists. If the commission is not sure about the reliability of the specialist's medical report, a second medical examination should be conducted. *The Guideline Book on Medical Commissions for Disability Assessment* regulates the methodology of work.

d) **Financing** - The Pension and Disability Fund are placed under the Ministry of Labour and Social Affairs and allocated to the Social Insurance Institute. The pension and disability allowances are indexed each time the budgetary wages are raised. The employer contributes 30% of the salary to the social insurance for the employee involved in a work accident, occupational disease and/or unemployment. The employee contributes 11% of their salary to maternity leave and pension.

PROTECTION OF DISABLED VETERANS

a) **Main legal documents** - Protection of war veterans is centralised under the jurisdiction of the Ministry of Defence and Ministry of Labour and Social Affairs. *The Law No. 7663 "On the status of disabled war veterans"* regulates veteran disability care.

b) **Rights**- Disabled war veterans enjoy financial rights such as: additional compensation from the disability pension, the right to assistance and care by another person paid by the local government and their pension is indexed according to the national wages index. The state may cover medical treatment expenses provided somewhere abroad for disabled war veterans, medical costs are completely reimbursed, and they can get all orthopedic devices for free. Associations of disabled war veterans are state subsidised.

c) **Assessment** - The Medical Commission for Assessment of Working Capacity makes the assessment of impairment. These commissions are under the jurisdiction of the state Social Service under the Department of Ministry of Labour and Social Affairs.

PROTECTION OF CIVIL VICTIMS OF WAR

There is no specific law on issues regarding civil victims of war in Albania.

EDUCATION

The education system in Albania is centralized. It is under the Ministry of Education and Science. There is no special department, section or service within the Ministry of Education dealing with special schools.

a) **Main legal documents** - The main law in the field of education in Albania is *Law No. 7952 "On the Pre-University Education System"* adopted on 21 June 1995. The third chapter of the law addresses special education. According to this legislation, special education is a part of the public education system and should guarantee the complete development of people with physical or intellectual disabilities in accordance with their needs. *The Normative Dispositions on Special Education in Albania*, a section of *Law No. 7952*, introduces the philosophy

⁷ Besim Nuri, "Health Care Systems in Transition: Albania," (Copenhagen: European Observatory on Health Care Systems, 2002).

⁸ This is only for people with disabilities who are not able to take care of themselves.

of integrated education in which the state will support the education of children with disabilities providing them educational opportunities in and out of mainstream schools. Under these dispositions, 8-years of education is compulsory for all children from 6-16 years. According to the Normative Dispositions, "children with disabilities can follow regular public schools with 1-2 children per class". Normative Dispositions also stipulate specific incentives for teachers who have children with disabilities in their classes, such as:

- For each disabled pupil, the number of pupils in class is decreased for 3;
- The teacher has 2 hours less from the week teaching program;
- The teacher can receive an additional allowance.

b) **Commissions for Categorisation** - Specialised Commissions for Categorisation of children with disabilities do not exist in Albania. The commissions assessing the capacity of children with disabilities are the same ones assessing the working capacity of adults with disabilities known as Medical Commissions for Assessment of Working Capacity. These commissions provide a medical report on the status of the child with disabilities. Based on this medical report, the child is placed into a special school and receives the disability payment. The report from the commissions does not necessitate acceptance of the child in special schools. Instead, special schools set up an Assessment Commission each time there is a request from a parent to place their child in a special school. This commission consists of the school director, two specialists from the school and a medical doctor.

c) **Special schools and special classes** - Special schools are under the authority of the Ministry of Education. According to the *Normative Dispositions on the Special Education in Albania*, chapter XIII, articles 62 and 63, the education of children with disabilities is done in two forms: in the frame of integrative education (in regular schools) and in special classes/schools. Special schools are part of the public pre-university institutional network in the Republic of Albania. The teaching programme implemented in special schools is the same as the one implemented in the public schools but it is adapted to the special needs of pupils.

Concerning integrative education, very few mainstream schools have special classes for children with disabilities. This is mainly school directors' initiatives rather than a standard for all schools. Even though, the Ministry of Education has called for the reform "Education for All", most mainstream schools refuse to have children with disabilities in their classes.

EMPLOYMENT

a) **Main legal documents** - There are two laws on employment promotion and vocational training: *Law No. 8872 "On Education and Vocational Training"*, and *Law No. 7995 "On Employment Promotion"*. These laws do not refer only to people with disabilities. It refers to the people who would like to have vocational training including people with disabilities, all students who finish compulsory education and all persons under 18 who are job seekers. There is a specific chapter for the employment of people with disabilities.

b) **Vocational training and rehabilitation** - Vocational training is legally possible for all people with disabilities if they can be prepared and have a certain prospective to keep an adapted job. Usually, this is not done in practice because of lack of by-laws and material support. The vocational training depends on the health condition and ability of a person. The state takes all necessary measures to develop specialised services for vocational training for people with disabilities who are asking to choose or change their job.

c) **Sheltered workshops** - The term sheltered work does not exist in Albanian legislation. In laws it is stated that workers with disabilities should have an adapted job according to their working capacity and one out of 24 employees should be a person with disabilities. One employer can recruit one person with severe disabilities instead of 5 persons with light disabilities. The employer can ask the state subvention to adapt the working place for people with disabilities and to provide them with essential job skills. The wage of the person with disabilities is tax-exempted.

ACCESSIBILITY

The legal documents on urban planning and construction are the *Law on Urbanism and Urbanistic Rules approved in 1998* and the *legal amendments approved in 1999, 2000 and 2003*. Specific laws on the status of people with disabilities stipulates that all public, health and social institutions should be adapted in order to be accessible for persons who have visual impairments or paraplegia. All new public constructions should be barrier-free for people with disabilities according to *Law No.7889 "On the status of invalids", article 13.2* adopted in 1994. According to these specific laws, people with disabilities can travel for free or pay a half price for city-transport tickets. In addition, each of these special laws calls for the adaptation of public transport stations and vehicles. These laws are an obligation for ministries to issue by-laws but no results can be seen yet concerning urban planning and transport. Within these laws there are no penalty provisions if the public institutions or transport are not adapted to be accessible.

ANTI-DISCRIMINATION

There is no anti-discrimination law on disability in Albania.

COUNTRY DISABILITY LEGISLATIVE OVERVIEW

BOSNIA AND HERZEGOVINA**GENERAL FACTS ABOUT BOSNIA AND HERZEGOVINA****People⁹**

Population (July 2004)	4,007,608
Population growth rate (2004)	0.45%

Government¹⁰

Country name	Bosnia and Herzegovina
Capital	Sarajevo
Constitution	The Dayton Agreement, signed 14 December 1995

Economy¹¹

GDP (2003)	purchasing power parity - \$24.31 billion
GDP real growth rate (2003)	3.5%
GDP - per capita (2003)	purchasing power parity - \$6,100
Unemployment rate (2002)	40%
Population below the poverty line	NA

Health¹²

Total health expenditure per capita (Intl \$, 2001):	268
Total health expenditure as % of GDP (2001):	7.5

GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES

Issues regarding people with disabilities are treated under several legislative regulations: social protection, protection of civil victims of war, protection of disabled veterans and families of fallen soldiers, health care and insurance, and pension and disability insurance. On the state level there is no legislation concerning disability except on an entity or cantonal level. The status of people with disabilities in Bosnia and Herzegovina is regulated through various legal acts:

1. Persons with acquired or congenital disabilities - entity / cantonal level
2. Civil victims of war - entity / cantonal level
3. Disabled veterans - entity level

The Council of Ministers adopted the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities on September 30th 2003 and the Council's decision entered into force on December 24th 2003.

SOCIAL WELFARE

In pre-war Bosnia and Herzegovina, social protection and social welfare were based on three basic pillars: employment, broad and universal social insurance, and social welfare systems which were tied to membership within centrally defined categories such as single parent headed households, people with disabilities and children¹³. Nowadays, social protection in Bosnia and Herzegovina is organised on the entity and cantonal level, meaning that each entity organises their social welfare systems.

a) **Main legal documents** - Within the Federation, the main legal document regulating social welfare is the "*Federation Law on the Basis of Social Protection, Protection of Civil Victims of War and Protection of Families with Children¹⁴*", which establishes the obligation for the cantons to enact their own legislation on social protection. Currently, only eight cantons have adopted such legislation while others have only draft versions of social protection laws. The cantons with only draft versions, therefore, have special decrees enacted by the cantonal government. In Republika Srpska, where the system is centralised, the *Law on Social Protection¹⁵* regulates the system of social welfare.

b) **Beneficiaries** - Social protection beneficiaries include, people with disabilities, people with physical and intellectual difficulties in development and civil victims of war¹⁶.

c) **Rights** - Social benefits include, financial and other kinds of material assistance (such as permanent financial

⁹ CIA - The World Fact Book - Bosnia and Herzegovina available at: www.cia.gov

¹⁰ Ibid

¹¹ Ibid

¹² World Health Organization available at: www.who.int

¹³ Department for International Development, "Bosnia and Herzegovina: Country Strategy Paper 2000-2003," (Department for International Development, September 2000).

¹⁴ The Federal Law was enacted on September 14th, 1999 ("Official Gazette of FBiH", no. 36/99)

¹⁵ "Official Gazette of Republika Srpska", no. 5/93 and 15/96

¹⁶ In the Federation, protection of civil victims of war is regulated through the social welfare system, and in Republika Srpska a separate law regulates this issue.

allowance, financial allowance for care and assistance by a third person, or other kinds of material assistance); training for work and independent living; placement within a foster family or social protection institutions; social welfare and other professional services; home-based care and assistance.

d) **Financing** - Within the Federation, funds for financing social protection and protection of civil victims of war come from the municipal budget, the cantonal budget, investments of institution founders, personal participation of beneficiaries, endowments and wills. In Republika Srpska, financial means are provided through the Republican and municipal budgets.

However, in a survey conducted in cooperation with DPO's from both entities entitled the "UN Standard Rules and Domestic Legislation", Centres for Civic Initiatives established that legislation in the Federation does not provide sufficient guarantees for the realisation of social welfare rights and it unjustifiably differentiates between people with disabilities based on the cause of their disability. In addition, rights guaranteed by legislation in Republic Srpska often cannot be realised in practice¹⁷.

HEALTH CARE AND INSURANCE

Before the war, Bosnia and Herzegovina, like the rest of the former Yugoslavia, had a sophisticated health care system. After the signing of General Framework Agreement for Peace in BiH, the health system of BiH was divided between the Federation of BiH and Republika Srpska, meaning that the organisation, delivery and financing of health care services became the sole responsibility of each entity¹⁸. Republika Srpska has a centralised health care system which is under the jurisdiction of the Ministry of Health and Social Welfare. In the Federation, the health care system is decentralised and each of the ten cantons provides primary and secondary health care through their own Ministries of Health.

a) **Main legal documents** - The main legal texts that regulate the health care systems are the "*Entity Laws on Health Care and Laws on Health Insurance*¹⁹".

b) **Rights** - Within the Federation every insured person has the right to a basic package of health and social services regardless the amount of resources available in a district or canton. Benefits included in the compulsory insurance are: primary health care, specialist consultative and hospital care, salary compensation during sick leave, and compensation for travel expenses related to medical care. Insured persons have the right to orthopedic and other devices, dental prosthesis and medicines that are on the list approved by the Ministry of Health. In Republika Srpska, insured persons may have access to rehabilitation in specialised institutions as an extension of hospital treatment but only if the authorised medical commission gives approval.

c) **Assessment** - The elected medical doctor from a primary health care institution estimates the period of temporary incapability to work. If the insured person is not satisfied with the decision, they can then make an appeal to the medical commission which makes the final decision.

d) **Financing** - Within the Federation, health care is mainly financed by funds coming from a health insurance scheme within the ten cantonal health insurance funds and one Federal Health Insurance Fund. The funds also come from taxes on salaries of employees in a legal entity or working in the private sector; taxes on the income of individuals working in profit or non-profit sectors; taxes on pension and disability allowance; cantonal or municipal budget, etc. In Republika Srpska, the Health Insurance Fund is responsible for the collection and allocation of financial contributions to health care providers. This single fund operates on the basis of solidarity and mutuality.

However, Centers for Civic Initiatives and DPO's maintain that people with disabilities have serious problems in the realisation of rights to health care and health insurance in both entities. Furthermore, the legislation within the Federation favours people with disabilities whose impairment had been caused by armed conflict in Bosnia²⁰.

PENSION AND DISABILITY INSURANCE

Each entity in Bosnia and Herzegovina has its own legislation in the field of pension and disability insurance.

a) **Main legal documents** - Laws that regulate the organisation and eligibility criteria of pension and disability insurance rights include, The *Law on Pension and Disability Insurance*²¹ and the *Law on Organisation of Pension and Disability Insurance*²². In Republika Srpska, pension and disability insurance are regulated by the *Law on Pension and Disability Insurance*²³.

¹⁷ DPOs in cooperation with Centres of Civic Initiatives, "UN Standard Rules and Domestic Legislation", (Centres of Civic Initiatives) 17- 19.

¹⁸ Andreja Subotica and David Wildman, "Bosnia and Herzegovina: Health Profile," (DFID Health Systems Resource Centre, June 2003).

¹⁹ Federation Law on Health Care ("Official Gazette of the Federation of BiH", no. 29/97), Federation Law on Health Insurance ("Official Gazette of the Federation of BiH", no. 30/97), RS Law on Health Care and RS Law on Health Insurance ("Official Gazette of Republika Srpska", no. 18/99).

²⁰ DPOs in collaboration with Centres of Civil Initiatives, "UN Standard Rules and Domestic Legislation", (Centres of Civic Initiatives): 6- 7.

²¹ "Official Gazette of the Federation of Bosnia and Herzegovina", no. 29/98

²² "Official Gazette of the Federation of Bosnia and Herzegovina", no. 32/01

²³ "Official Gazette of Republika Srpska", no. 32/2000, enacted in September 2000

b) **Rights** - Rights from pension and disability insurance in the Federation include the right to old age pension, the right to disability pension, the right to family pension, and rights of insured persons who have changes in their work capabilities. These rights may be realised through the Federal Institute for Pension and Disability Insurance. With compulsory pension and disability insurance, insured persons in Republika Srpska are eligible for benefits in the case of old age, a decrease or complete loss of working capacity or death.

c) **Assessment** - Assessment of working capacity is carried out by an expert commission from the Pension and Disability Insurance Fund.

d) **Financing** - Pension and disability insurance is financed through contributions from salary or earnings, voluntary insurance, and other sources. Contribution sources for the pension and disability insurance include contribution from salaries and other incomes from insured persons; contributions from one's salary paid by the employer; or additional contributions for the period of insurance calculated as double.

PROTECTION OF DISABLED VETERANS

a) **Main legal documents** - Each entity has its own legislation on the protection of disabled war veterans but the basis for these laws is taken from the former Yugoslav law adopted in 1986. In the Federation it is called the "*Law on the Basic Rights of Disabled Veterans and Families of Fallen Soldiers*²⁴", in Republika Srpska it is the "*Law on the Rights of Veterans, Military Disabled and Families of Fallen Soldiers*²⁵".

b) **Rights** - Disabled veterans have the right to personal disability allowance, allowance for care and assistance by a third person, orthopedic allowance, health care and other rights related to the health care, orthopedic and other devices, medical treatment and rehabilitation in a spa and rehabilitation centre, free and privileged transport, the right to import a motor vehicle, priority in employment, priority in solving housing problems, tax exemptions, vocational training, and participation in the privatisation process. In the Federation, the Ministry of Veterans' Affairs pays the allowances to disabled war veterans through its cantonal offices and in Republika Srpska the Ministry of Labour, Veterans and War Victims is in charge of the payment to disabled veterans.

c) **Assessment** - Authorised medical commissions make an assessment on the disabled veteran's impairment and in order to determine the right to allowance for care and assistance by a third person and the right to orthopedic devices.

PROTECTION OF CIVIL VICTIMS OF WAR

a) **Main legal documents** - In the Federation, protection of civil war victims is integrated in the "*Federal Law on the Basis of Social Protection, Protection of Civil Victims of War and Protection of Families with Children*", enacted in 1999²⁶. Republika Srpska has a separate law called the "*Law on Protection of Civil Victims of War*²⁷".

b) **Rights** of civil victims include, civil disability allowance (i.e. family disability allowance); orthopedic allowance; allowance for care and assistance by another person; allowance for the family member incapable of working; additional financial assistance; allowance for a single beneficiary; health care; vocational training; financial support to cover the costs of treatment and procurement of orthopedic devices; and child allowance. In the Federation, Centres for Social Work are in charge of payments for civil war victims, and in Republika Srpska, the Ministry of Labour, Veterans and War Victims pays the benefits to civil war victims.

EDUCATION

According to the General Law on Primary and Secondary Education in Bosnia and Herzegovina, all the children have the right to equal education and there should not be any type of discrimination. Primary education is compulsory for all children and it lasts for 9 years²⁸. Article 19 of the *General Law on Primary and Secondary Education in Bosnia and Herzegovina* states, "Children and youth with special educational needs should acquire education in regular schools according to the curricula that is adapted to their individual needs... Children and youth with severe difficulties in development may be partially or completely educated in special educational institutions."

a) **Main legal documents** - In Republika Srpska the education system is covered by entity legislation, and there are separate laws for each of 4 levels of education (pre-school, primary, secondary and tertiary). In the Federation, education is regulated by legislation at the cantonal level. Each of the ten cantons has their own legislation on pre-school, primary and secondary education, and the cantons with universities have the legislation on higher education.

b) **Commissions for Categorisation** - The work of the commissions for the assessment and classification of children with disabilities and their eligibility for special education is largely dominated by a medical model. Commissions for assessment are mainly placed in Centres for Social Work.

c) **Special schools and special classes** - Bosnia and Herzegovina inherited the structure of its educational system from the former Yugoslavia which had a highly developed system of separate institutions, schools and

²⁴ "Official Gazette of the Republic of BiH", no. 2/92 and 13/94

²⁵ "Official Gazette of Republika Srpska", no. 35/99

²⁶ "Official Gazette of FBiH", no. 36/99

²⁷ The Law on Protection of Civil Victims of War ("Official Gazette of Republika Srpska", no. 25/93)

²⁸ "Official Gazette of Bosnia and Herzegovina", no. 59/03, article 4

classes particularly in urban areas²⁹. In Bosnia and Herzegovina children with special needs are not sufficiently integrated into mainstream school programmes³⁰. Until recently, segregated special education for people with disabilities was the norm in both entities in Bosnia and Herzegovina. In the Federation the *General Law on Primary and Secondary Education* is in accordance with UN Standard Rules on the Equalisation of Opportunities for People with Disabilities, can provide sound basis for the reforms of the education system. In Republika Srpska however, a thorough reform of the education system for people with disabilities is needed as the current system hardly satisfies their needs.

EMPLOYMENT

Constitutions for both Republika Srpska and Bosnia and Herzegovina stipulate the right of all citizens to work and the freedom to choose the type of work.

a) **Main legal documents** - The Constitution of Bosnia and Herzegovina stipulates that the entities are responsible for of labour and employment. In the Federation, the *Labour Law no. 43/99*³¹ stipulates that a person seeking for employment should not be discriminated on the basis of race, colour, religion [...] and physical or mental disability. Also, Article 6 stipulates that employees shall be entitled to health care, other forms of social security and additional rights in case of disease, decrease or loss of working ability and old age. The reform of legislation in the area of labour and employment in Republika Srpska was carried out in 2000, through the adoption of the *Labour Law* and the *Law on Employment*, as a part of systematic regulations in this area³².

b) **Sheltered workshops** - The system of sheltered workshops in which people with disabilities could be employed is still not well developed.

ACCESSIBILITY

The *Law on Building*³³ and the *Rule Book on Free Mobility of People with Disabilities* regulate building and construction in Bosnia and Herzegovina. Buildings, public institutions and services have to be planned and designed in a way that provides free access and mobility of people with disabilities.

ANTI-DISCRIMINATION

There is no anti-discrimination law on disability in Bosnia and Herzegovina.

²⁹ Martyn Rouse, Lani Florian, and Jane Connolly, "Special Classrooms for Children with Disabilities in Bosnia and Herzegovina 1997-2000 - Final External Evaluation of the Project - Final report 2000" (UNICEF, Mediciens du Monde, and the Kennedy Foundation: Cambridge, December 2000).

³⁰ Poverty Reduction Strategy Paper for Bosnia and Herzegovina, Sectoral Priorities - Education

³¹ "Official Gazette of FBiH", no. 43/99

³² Poverty Reduction Strategy Paper for Bosnia and Herzegovina

³³ "Official Gazette of BiH", no. 55/02

COUNTRY DISABILITY LEGISLATIVE OVERVIEW

FORMER YUGOSLAV REPUBLIC OF MACEDONIA**GENERAL FACTS ABOUT THE FORMER YUGOSLAV REPUBLIC OF MACEDONIA****People³⁴**

Population (July 2004)	2,071,210
Population growth rate (2004)	0.39%

Government³⁵

Country name	The Former Yugoslav Republic of Macedonia
Capital	Skopje
Constitution	Adopted on 17 November 1991

Economy³⁶

GDP (2003)	purchasing power parity - \$13.81 billion
GDP real growth rate (2003)	2.8%
GDP - per capita (2003)	purchasing power parity - \$6,700
Unemployment rate (2003)	36.7%
Population below the poverty line (2002)	30.2%

Health³⁷

Total health expenditure per capita (Intl \$, 2001):	331
Total health expenditure as % of GDP (2001):	6.8

GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES

The rights of people with disabilities in Macedonia are protected by general legislation and a special law called *The Law on the Employment of Persons with Disabilities*. Regarding the judicial mechanism adopted to protect the rights of people with disabilities the government states, "In legal and sub-legal acts there is an appeal procedure to realise their rights". The general legislation applies to persons with various types of disabilities with respect to education, employment, and the right to marriage, the right to parenthood/family, political rights, the right to privacy, and property rights. The laws guarantee the following benefits to people with disabilities: health and medical care, vocational training, rehabilitation and counselling, financial security, employment, independent living, and participation in decision-making.

The Constitution of Macedonia (paragraph 3, article 35) prescribes that the state is responsible for creating conditions for inclusion of people with disabilities in the society. The National Strategy on Achieving Equal Rights of People with Disabilities in Macedonia has been adopted as well and it is based on the UN Standard Rules for Equalization of Opportunities for People with Disabilities.

SOCIAL WELFARE

- a) **Main legal documents** - On the national level, the majority of rights of people with disabilities are regulated within the Law on Social Protection No. 16/2000³⁸.
- b) **Beneficiaries** - According to Article 21 of the *Law on Social Protection*, people with moderate, severe and profound intellectual disabilities who are incapable of work are entitled to a permanent form of material assistance, if they are not already covered by some other form of social protection.
- c) **Rights** - Within the *Law on Social Protection* people with disabilities are entitled to the following rights:
 - **Social Prevention** (includes primary health care, prenatal and postnatal care, programs on prevention of accidents in various fields),
 - **Non-Institutional Care** (social services to social welfare beneficiaries, assistance to a person, home care and assistance to a person or a family, day care assistance to a person or a family and placement into a foster family),
 - **Institutional Care** (the right to receive training for work and productive activity and the right to be placed in a social institution),
 - **Right to Social Assistance** (continuous financial assistance to persons with working ability unproved, financial allowance for assistance and care by another person, right to health care, reimbursement of salary for shortened working hours due to taking care of a child with disabilities, single financial assistance or assistance in kind, the right to housing).
- d) **Financing** - The social welfare financing resources are provided from the budget of the Former Yugoslav

³⁴ Source: Website of CIA - The World Factbook - FYR of Macedonia (www.cia.gov)

³⁵ Ibid

³⁶ Ibid

³⁷ Source: Website of World Health Organization (www.who.int)

³⁸ "Official Gazette of the Republic of Macedonia " No. 16/2000.

Republic of Macedonia. In addition, financing resources come from contributions from the beneficiaries and their relatives who are obliged to support them through changes for services, gifts, legacies and other sources according to the law.

HEALTH CARE AND INSURANCE

a) **Main legal documents** - Article 39 of the *Constitution of the Republic of Macedonia* and Article 3 of the *Law on Health Care*³⁹ ensures the right to medical care for all citizens. The *Law on Health Insurance*⁴⁰ regulates the health insurance of citizens, as well as the rights and duties deriving there from.

b) **Rights** - Within the Law on Health Insurance, compulsory insurance includes beneficiaries of pensions and financial compensation, disabled veterans and civil victims of war, according to the regulations anticipated by Pension and Disability Insurance. The main benefit that Health Insurance Fund beneficiaries receive is every day medical treatment from general practitioners. The Health Insurance Fund covers the costs as well for hospitalisation, operations and rehabilitation. The main health services, according to the law, are: prosthesis, orthopaedic and other supplies and materials. With the newest regulation modifications, the previously required participation from beneficiaries for orthopaedic supplies is reduced from 40% to 10% (only for those above age 18, whilst for children under 18 receive them free of charge). A person with disabilities can stay in a rehabilitation centre only once a year for a total of 3 weeks or 21 days.

People who are dependent on continuous financial assistance who are placed either in residential institutions for social protection or who live in foster families are also insured. According to this law, people with disabilities are eligible to receive health coverage (or insurance) as beneficiaries of regular social security, if they are not insured through one of their parents.

c) **Financing** - Compulsory contributions levied by the Health Insurance Fund are the main health care funding sources, accounting for 82.9 % of the health care financing sources. Users' co-payments and cash payments account for 13 %, and the state budget accounts for 2.2 % (figures from 1997)⁴¹.

PENSION AND DISABILITY INSURANCE

a) **Main legal documents** - The *Law on Pension and Disability Insurance*⁴² regulates mandatory pension and disability insurance for employees. Through mandatory pension and disability insurance based on employment and according to the social equity principle, ensuing rights are fulfilled in cases of old age, reduction and loss of working ability, death and physical injury.

b) **Rights** - Pension and disability insurance encompasses: right to old age pension; right to disability pension; right to reassignment of employment; right to corresponding employment - the right to vocational training or improvement of skills and right to appropriate money allowances; right to family pension; right to financial allowance for physical injury; and right to the lowest pension level.

c) **Assessment** - Pension and disability rights are based on the following: the loss of working capacity, the remaining working capacity, the physical injury, the need for support and care and working disability as a basis for receiving family pension. The assessment of disability is based on a medical diagnosis, opinions and examinations conducted by the Commission for Assessment of the Working Capacity. The commission is usually formed within the Pension and Disability Insurance Fund.

d) **Financing** - The Pension and Disability Insurance Fund operates under the Ministry of Labour and Social Policy. Like most countries in the region, the Republic of Macedonia has a pension and disability insurance system based on the "pay-as-you-go" principle.

SOCIAL PROTECTION OF DISABLED VETERANS

a) **Main legal documents** - Disabled veteran social protection is regulated within the *Law on Rights of Disabled Veterans, Members of their Families, and Members of the Families of Deceased Veterans*⁴³. Means to achieve and implement the rights set by this law are provided from the republican budget.

b) **Rights** - Veterans disabled in wars, peacetime veterans, members of their families, and members of the families of deceased veterans have the following rights: personal disability pension, family disability pension and increased family pension, disability supplement, allowance for care and treatment by another person, orthopaedic allowance, spa and climatic treatment, right to a motor vehicle, child allowance, professional rehabilitation, health protection, help in case of death and free and privileged transport.

PROTECTION OF CIVIL VICTIMS OF WAR

The *Law on Civil Victims of War*⁴⁴ regulates the status and rights of civil victims of war. The amount of civil disability pension of disabled civilians from war is determined as follows:

³⁹ "Official Gazette of the Republic of Macedonia", no. 21/1998.

⁴⁰ "Official Gazette of the Republic of Macedonia", no. 25/2000.

⁴¹ S. Hajoiff S, G. Pecelj, and F. Tozija, "Health Care Systems in Transition: The Former Yugoslav Republic of Macedonia", (Copenhagen: The European Observatory on Health Care Systems, 2000).

⁴² Promulgated on 27 December 1993.

⁴³ "Official Gazette of the Republic of Macedonia", No.13/96.

⁴⁴ "Official Gazette of the Republic of Macedonia", No. 38/91 and 81/99.

- I group - 50% of the personal disability pension of the first group of disabled veterans who receive care and support by another person,
- II group - 73% of the civil disability pension of the first group civilians disabled in war,
- III group - 55% of the civil disability pension of the first group civilians disabled in war,
- IV group - 40% of the civil disability pension of the first group civilians disabled in war,
- V group - 30% of the civil disability pension of the first group civilians disabled in war.

EDUCATION

Article 44 of the *Constitution* stipulates that, "Everyone has the right to education. Education is available to everyone under equal conditions. Primary education is compulsory and free of charge".

a) **Main legal documents** - The Law on Primary Education⁴⁵ and the Law on Secondary Education⁴⁶ ensures that the education for people with disabilities is an integral part of the national educational program. The educational system is organised by the Ministry of Education, which is still highly centralised administratively. Higher education is regulated by a Draft Law on Higher Education⁴⁷ with a special emphasis on article 157 on the rights of the students, stating that students have the following rights:

Students completing a Ph.D. and/or students specialising in a specific field, who fall under the following categories: students who do not have parents, who are blind, deaf, or are within the first- or second- group of people with disabilities, those who are mothers with children 6 years and under and/or those who are being treated in hospital shall have the right to special advantages determined by the bylaws of the higher education institution concerned.

b) **Commissions for Categorisation** - Commissions for diagnosing, estimating and arranging adequate treatment for people with disabilities were formed in 1961.

c) **Special schools and special classes** - According to the legislation on education, there are special schools, as well as special classes within the mainstream primary schools for children with disabilities. With the adoption of the Salamanca Convention, the government has taken the first steps in for the country to establish and implement inclusive education for children with disabilities in practice, in five pilot schools. Special classes in mainstream schools were first established in 1953, and there are currently 80 such classes throughout the country. Special protection workshops have been established in various cities.

Concerning inclusive education, integration into the mainstream system of education for children with disabilities depends on the level of their disability. According to Article 25 of the *Law on Primary Education*, the right to compulsory primary education is guaranteed for children with light intellectual disabilities through the existence of special programmes. Furthermore, according to Article 39 of the *Law on Secondary Education*, vocational training for children with light intellectual disabilities is provided through the implementation of special programmes in two schools, which provide residential accommodation (in Skopje and Stip). It can be stated that the government of the Republic of Macedonia pays particular attention to the improvement of education of children with disabilities through its educational policy and implementation of specific programmes.

EMPLOYMENT

a) **Main legal documents** - The *Law on the Employment of Persons with Disability*⁴⁸ regulates the conditions for the employment of people with disabilities. Article 5 of this law states that when an employer hires a person with disabilities, they are obliged to create suitable conditions and adapt the workplace. Support can be obtained from a Special Fund which is established within the Republican Institute for Employment, in order to cover possible extra costs of adapting workspaces.

In favour of financing activities for providing conditions for employment of people with disabilities, the Special Fund is dedicated to the adaptation of working spaces and the procurement of equipment including, instruments, apparatuses, spare parts and tools to ensure suitable and accessible working environments for people with disabilities. Fifteen percent of the total amount of the money from the contribution for employment (of the general population) is dedicated to the Special Fund within the Employment Bureau. The money for the Special Fund also comes from: VAT, donations and other sources.

b) **Vocational training and rehabilitation** - The *Law on Secondary Education* provides for the training of people with mild intellectual disabilities in terms of vocational-occupational activities in the two existing special schools (in Skopje and Stip). The *Law on Social Protection* ensures the right to vocational training for people with moderate to severe intellectual disabilities. This training is conducted both in the Institute for Rehabilitation of Children and Youth in Skopje and on the national level.

c) **Sheltered workshops** - In Macedonia there are 380 sheltered companies. Article 9 of the *Law on Employment of Persons with Disability* regulates the conditions for the creation of a sheltered company which are as follows: a minimum of 5 employed people are required for the creation of one company; 40% of the employees have to be people with disabilities or people with decreased working abilities. From those 40%, a minimum of at least

⁴⁵ "Official Gazette of the Republic of Macedonia", No. 82/99.

⁴⁶ Both laws are within "Official Gazette of the Republic of Macedonia", No. 82/99.

⁴⁷ "Official Gazette of the Republic of Macedonia", No. 64/2000, 3rd August 2000.

⁴⁸ "Official Gazette of the Republic of Macedonia", No. 44/2000.

half of the people employed have a disability including: a visual impairment, a hearing impairment, a physical disability, a mental disability, persons with combined disabilities and persons with psychoses, who because of the nature and the degree of the impairment have special needs for suitable working conditions.

A large percentage of the sheltered workshops are members in the Union of Sheltered Workshops, which has existed since 1970. The main roles of the Union are:

To create a balance of interests between the employers and the rights of the employees,

- Protection of the employees, no matter if they are disabled or not,
- In the case of not respecting the rights of the employees or abuse of the money from the Special Fund, the Union has only a counselling role to inform the responsible structure (in this case the Labour's Inspection),
- To support the person with disabilities as an employer, not as an employee,
- Monitoring of the conditions for work for people with disabilities in the sheltered companies, if those special conditions are required,
- To give an opinion in case the employer wants to use money from the Special Fund for employment of people with disabilities. If the Union confirms the need for adaptation of the working place or need for adapted machines, than the Union supports the employer to get the money from the Special Fund.

ACCESSIBILITY

Using the Regulation on Standards and Norms for Spatial Planning and the Regulation on Standards and Norms for Projecting Infrastructures in Urban Areas, the state plans to prepare the creation of conditions enabling the free movement of people with disabilities. The Ministry of Transport and Communications has improved accessibility conditions for people with disabilities by granting permission only for the construction of buildings with architectural plans that follow the norms and standards that permit easy access.

There is no regulatory or sub-legal act in the Republic of Macedonia that ensures the availability of, and access to, public information for people with intellectual disabilities. There are no rules to ensure accessibility to the built environment and no measures have been adopted to ensure accessibility within the built environment. Special transport includes transport free of charge for school children and it is available for medical treatment, education, work and recreational purposes. When planning to build accessible environments the most difficult obstacles are attitudinal factors, economic/budgetary factors, lack of legislation and regulations, and lack of enforcement mechanisms. There is no disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people is not officially recognised and is not used as the first language in the education of deaf people but is recognised as the main means of communication between deaf people and others. The following services are provided in order to facilitate information and communication between people with disabilities and others: literature in Braille/tape, news magazines on Braille/tape, sign language interpretation being available for major events and easy readers for persons with intellectual disabilities.

ANTI-DISCRIMINATION

There is no separate anti-discrimination law on disability in Federal Republic of Macedonia. For the moment, Polio Plus, a Macedonian NGO and the Inter-Parliamentary Lobby Group (IPPLG) are working on working on drafting *lex generalis* (a comprehensive law) which will consist of general provisions concerning the rights of people with disabilities. In this *lex generalis* special emphases will be put on:

- Mechanisms for protection of the rights listed in the law (i.e. establishing a Disability Rights Commission and a governmental body on disability),
- Funds – especially for mechanisms to be implemented.

This comprehensive law will produce several *lex specialis*, which will elaborate different spheres of interest for people with disabilities in the Republic of Macedonia. This new comprehensive law will consist of all laws that concern people with disabilities and will also include anti-discrimination laws on disability.

COUNTRY DISABILITY LEGISLATIVE OVERVIEW

SERBIA AND MONTENEGRO**GENERAL FACTS ABOUT SERBIA AND MONTENEGRO****People⁴⁹**

Population (July 2004)	10,825,900
Population growth rate (2004)	0.03%

Government⁵⁰

Country name	Serbia and Montenegro
Capital	Belgrade
Constitution	Adopted on 4 February 2003

Economy⁵¹

GDP (2003)	purchasing power parity - \$23.89 billion
GDP real growth rate (2003)	1.5%
GDP - per capita (2003)	purchasing power parity - \$2,200
Unemployment rate (2002)	34.5%
Population below the poverty line (1999)	30%

Health⁵²

Total health expenditure per capita (Intl \$, 2001):	616
Total health expenditure as % of GDP (2001):	8.2

THE REPUBLIC OF SERBIA**GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES IN SERBIA**

In Serbia, protection of people with disabilities is provided through various systems such as, pension and disability insurance, health care and insurance, employment and vocational training, education, social welfare, urbanism and planning, protection of war veterans and civil victims of war. The social security system in Serbia includes: pension and disability insurance, health insurance and unemployment insurance.

Since 2000 there has been a gradual shift towards a human rights perspective in the legislation that prescribes the status of people with disabilities. Organisations of people with disabilities and the civic sector brought about this change and Ministry for Social Affairs (2001- 2003) and Ministry for Labour, Employment and Social Affairs (2004) supported this shift of paradigm.

The situation and needs of people with disabilities was analysed in the Poverty Reduction Strategy Paper of Serbia in 2003. DPO's were actively involved in the process of drafting of PRSP, thus contributing to inclusion of the disability dimension within the final document. The National Strategy for People with disabilities is being currently drafted in Serbia as well. The strategy is based on the PRSP, the UN Standard Rules and other relevant international documents. Serbia is influencing the active participation of Serbia and Montenegro in the process of drafting of the UN Convention on Protection and Promotion of Rights and Dignities of People with Disabilities. Serbia and Montenegro is the regional leader contributing to the development of the UN Convention, providing a DPO expert as spokesperson for Serbia and Montenegro's state delegation in the Ad Hoc Committee for drafting of the Convention.

SOCIAL WELFARE

a) **Main legal documents** - Concerning social welfare, the Republic of Serbia has a complex system which covers social payments, family protection, childcare, care for elderly and people with disabilities. The *Law on Social Protection and Provision of Social Security of the Citizens*⁵³ governs the system of social protection. It guarantees the various benefits in the area of social welfare and also regulates the establishment of social welfare institutions. The Ministry of Labour, Employment and Social Affairs is in charge of the functioning of the social welfare system in Serbia.

b) **Beneficiaries** - According to the *Law on Social Protection*, social welfare beneficiaries include: people with complete incapacity to work (defined by the regulations on pension and disability insurance); persons not able to care for themselves due to disability or illness; children and youth with disabilities or difficulties in development.

⁴⁹ Source: Website of CIA - The World Fact Book - Serbia and Montenegro (www.cia.gov)

⁵⁰ Ibid

⁵¹ Ibid

⁵² Source: Website of World Health Organization (www.who.int)

⁵³ "Official Gazette of the Republic of Serbia", No. 36/91, 79/91, 33/93, 53/93, 67/93, 46/94, 52/96 and 29/01, and amended again in summer of 2004.

c) **Rights** - The right to social benefits is regulated by the *Law on Social Protection and Provision of Social Security of the Citizens* and includes: financial assistance for the family (MOP), allowance for care and assistance of another person, allowance for vocational training, home care and assistance, day care, placement in a social institution or a foster family, social welfare services, equipment for the beneficiary for placement in the social institution or foster family and a one-time financial allowance.

d) **Financing** - Social welfare benefits and the entire system of social welfare are financed from the Republican and municipal budgets.

HEALTH CARE AND INSURANCE

a) **Main legal documents** - The *Law on Health Care*⁵⁴ and the *Law on Health Insurance*⁵⁵ regulate the health care system in Serbia. Health care includes: prevention, diagnosis, therapy and rehabilitation in health institutions, including transportation in urgent cases, medicine, additional material used for medicine, medical material and orthopedic devices according to the medical implications⁵⁶. The government of the Republic of Serbia regulates the implementation of health care and it is financed through the Republican budget.

b) **Rights** - The Serbian *Law on Health Insurance* regulates the rights to health insurance for employees and other citizens included in the compulsory health insurance system. Health insurance rights include: health care, salary compensation during the period when the person is temporary unable to work, travel expenses and compensation related to health care and compensation for burial expenses.

Insured persons are provided with general and specialised medical rehabilitation. General medical rehabilitation may be provided in the Dom Zdravlja or General Hospital, i.e. a different medical institution that provides physical medicine and rehabilitation. Specialised medical rehabilitation may be provided in the medical institutions for specialised rehabilitation (such as a specialised hospital, institute, or clinic). Specialised medical rehabilitation can only be provided as a continuation of hospital treatment when the functional impairment cannot be prevented with general rehabilitation.

c) **Financing** - The most important source of health care financing is the publicly-owned compulsory health care insurance, the Health Insurance Fund (HIF). Additional sources are the Republican budget (which is paying for the care services of uninsured citizens, for preventive measures and special programs) and individual financial participations.

PENSION AND DISABILITY INSURANCE

a) **Main legal documents** - The *Law on Pension and Disability Insurance*⁵⁷ states that insured persons can realise their rights from compulsory pension and disability insurance in case of old age, disability, death and physical injury.

b) **Rights** - Rights from pension and disability insurance:

1. In case of old age - the right to old age pension;
2. In case of disability - the right to disability pension;
3. In case of death: a) the right to a family pension and b) the right to compensation for burial expenses;
4. In case of physical injury caused by an accident at work or an occupational disease - the right to compensation for physical injury.

c) **Assessment** - Insured person achieves rights through the Pension and Disability Fund. Request for achievement of right to pension should be submitted to this Fund. In order to decide on a person's right to pension and disability insurance and to confirm the existence of a disability, a physical injury, the cause of disability and/or physical injury, or complete inability to work and inability to live and work independently, the Pension and Disability Fund relies on an assessment given by medical experts. The *General Act of the Fund* regulates their work. This assessment can be given by a chosen doctor and the suggestion should be verified by a medical commission within the Health Institution (this commission is named by the Ministry in charge for health issues).

d) **Financing** - Pension and disability insurance is provided by the Pension and Disability Fund which is a legal entity for the achievement of rights from pension and disability insurance and provision of allowances. The Republican Government is directly in charge of the administration and organisation of the fund.

PROTECTION OF DISABLED VETERANS

a) **Main legal documents** - The *Federal Law from 1998*⁵⁸ regulates the rights of disabled veterans, families of killed soldiers and families of disabled veterans.

b) **Rights** of disabled veterans includes: personal disability allowance, allowance for care and assistance by a third person, orthopedic allowance, health care and other rights related to health care, orthopedic and other devices, compensation of salary during the period of unemployment, treatment in a spa, free and privileged

⁵⁴ "Official Gazette of the Republic of Serbia", No. 17/92

⁵⁵ "Official Gazette of the Republic of Serbia", No. 17/92

⁵⁶ Law on Health Care, article 7.

⁵⁷ "Official Gazette of the Republic of Serbia", No. 34/03.

⁵⁸ "Official Gazette of FRY", No. 24/98

transport, compensation for food and accommodation during a stay in another place, and the right to motor vehicle. Disabled veterans protection is financed from the federal budget. Extended protection of these categories is regulated by republican authorities and additional protection is regulated by local authorities.

PROTECTION OF CIVIL VICTIMS OF WAR

a) **Main legal documents** - The rights of civil victims of war are regulated by the *Law on Rights of Civilians Disabled in War*⁵⁹.

b) **Rights** - The rights of civil victims of war include: personal disability allowance, allowance for care and assistance by another person, an orthopedic allowance, health care and other rights related to health care, free and privileged transport, compensation for food and accommodation during a stay in another place, a monthly cash allowance, compensation for burial expenses. Financing for protection of civil victims of war comes from the republican budget. Cities or municipalities may also arrange additional benefits for civil victims of war.

EDUCATION

a) **Main legal documents** - Education of children and youth with disabilities is regulated by the regulations on primary and secondary school in the *Law on Principles of Educational System in Serbia*. This legislation was adopted in 2003 and amended in 2004 and regulates the systems of pre-school, primary and secondary education. Article 2 of this law states that educational system in Serbia should provide the following: equal opportunities for the education of children and pupils with difficulties in development". The law prohibits any form of discrimination and guarantees the right to education for all the citizens. Primary education is compulsory and free of charge. People with difficulties in development and people with disabilities have the right to education that will take into consideration their special educational needs. For people with hearing impairments, lectures in sign language are provided.

Primary education for children with difficulties in development lasts for nine years, according to the curricula of primary school or special curricula. Secondary education lasts for two, three or four years, according to the curricula of secondary school or special curricula. The law on universities that is still in power does not deal with the status of students with disabilities. However a new law on higher education is being prepared and several existing drafts take into account the needs of students with disabilities.

b) **Commissions for Categorisation** - A child with difficulties in development is included in the system of education according to the decision made by the Commission for Categorisation. The assessment made by the Commissions for Categorisation is based on the findings of a medical team of experts and covers the type and level of disability; the capacity to receive primary education and the type of school the child should attend. Once the assessment is made, the local authorities verify the decision. Categorisation of children is still done according to the *Decision on Criteria for Categorisation of Children with Difficulties in Development*⁶⁰. A new Decree is being drafted to amend the categorisation process by taking into account the principles embodied in the Convention on the Rights of the Child and the DCP, but it has not been adopted.

c) **Special schools and special classes** - In Serbia, there are 52 special schools with approximately 5791 pupils. There are also 196 special classes in 69 regular schools with 1283 pupils. There are 200 children in 26 groups either in special pre-schools or kindergartens.

EMPLOYMENT

a) **Main legal documents** - According to the *Law on Employment and Achievement of Rights for Unemployed Persons*⁶¹ it is possible to establish a programme for employment of people with disabilities. The *Law on the Basis of Employment in Federal Republic of Yugoslavia* regulates the relationship between employer and employee. According to article 3 of this law, people with disabilities enjoy special protection at work. The employer is obliged to provide a workplace according to the person's residual abilities and for which the person with disabilities is trained. The *Labour Law of the Republic of Serbia*⁶² regulates the rights, obligations and responsibilities related to work. Article 12 of this law prohibits any kind of discrimination such as gender, language, race, nationality and confession of the person seeking employment. Discrimination on the basis of disability is not specifically mentioned. People with disabilities can be employed in the open labour market under general conditions unless a law prescribes otherwise. It is possible for the parent who has a child with disabilities to get a paid leave in order to take care of the child up to when the child is five years of age maximum. The authorised commission that assesses the level of the psychophysical impairment of the child establishes this right. The law prescribes the protection of people with disabilities in a separate chapter, but it that chapter deals solely with people whose impairment has been caused by a professional illness or an accident at work and it does not cover other origins of disability.

b) **Vocational training and rehabilitation** - According to the type and level of disability, individuals may achieve the right to vocational training. Those who have finished primary school may be educated and trained for work in secondary schools. After the training they could get a job either in the open labour market or in sheltered

⁵⁹ "Official Gazette of the Republic of Serbia", No. 52/96

⁶⁰ Adopted by the Executive Council of Socialist Republic of Serbia in 1986.

⁶¹ "Official Gazette of the Republic of Serbia", No. 22/92, 73/92 and 82/92.

⁶² Adopted by the Serbian Parliament in December 2001.

workshops. Individuals who are not capable of receiving either theoretical or practical education are assigned to specialised sheltered workshops where they can be trained for simple jobs. Those who are not capable of any type of simple profession or job, have the right to continue their vocational training in Day Care centres. Day Care centres are not developed yet in all municipalities, only in bigger cities.

*Law on Vocational Training and Employment of People with Disabilities*⁶³ regulates the vocational training and employment of people with disabilities and people with difficulties in development. Originally, the term used in the law for both categories was "invalid". The right to vocational training and employment includes: children and youth with difficulties in development who cannot acquire education according to the curricula for students with difficulties in development; children and youth with difficulties in development who acquired their education according to the curricula for students with difficulties in development; disabled workers who cannot get the re-training or additional training

b) **Sheltered workshops** - The *Law on Vocational Training and Employment of People with Disabilities* establishes the possibility for establishing companies for vocational training and employment of people with disabilities. These companies are called "sheltered workshops". The law states that at least 40% of the employees should be people with disabilities; the space and equipment should be adapted to the needs of people employed there. The Republican Pension and Disability Insurance Fund, together with the former Ministry of Social Affairs, is the founder of sheltered workshops. Financial means for the functioning of these workshops comes from the republican budget. The Union of Protected Workshops coordinates the link between the government, the PIO Fund and sheltered workshops⁶⁴.

In 2003 the former Ministry of Labour and Employment drafted a new *Law on Employment of People with Disabilities*. In 2004, the Ministry of Labour, Employment and Social Affairs set up a working group to prepare a new draft of Law on Employment of People with Disabilities. Representatives of organisations of people with disabilities have been nominated to participate in the working group.

ACCESSIBILITY

Since the *Ordinance on Conditions for Planning of Buildings Related to the Accessibility for Elderly Persons, Children and People with disabilities*⁶⁵ that contained accessibility standards, but there are no provisions on sanctions for those who do not comply with the standards. It was necessary to amend the legislation and provide for sanctions and in 2003 the Ministry for Urban Planning and Construction included some of the amendments proposed by organisations of people with disabilities in its' draft of *Law on Construction and Planning*⁶⁶. The Serbian Parliament adopted the Law in 2003. The Law prescribes that new buildings must be in accordance with technical standards, or no building permit will be issued. It also prescribes that those who have designed or constructed buildings that are not in accordance with the technical standards can be fined. According to the Ministry's interpretation, the technical standards include accessibility standards prescribed for by the ordinance. If, for example, a Members of Engineers' Association that does not work in accordance with professional and ethical standards can lose their license to design buildings⁶⁷.

The Serbian Parliament adopted the *Law on Public Information*⁶⁸ in 2003. The law prescribes that the state and local authorities are obliged to provide access to information for people with disabilities.

ANTI-DISCRIMINATION

The Parliaments of Serbia, Montenegro and Federal Republic of Yugoslavia adopted the Constitutional Charter and Minority and Human Rights of Charter of Serbia and Montenegro early in 2003. Clause 3 of article 3 of the Minority and Human Rights Charter of Serbia and Montenegro prohibits discrimination on the basis of physical and intellectual disabilities. This clause was adopted after the campaign for the inclusion of an anti- discrimination clause that organisations of people with disabilities in Serbia lead in the summer of 2002.

The Ministry for State Administration and Local Autonomy of Serbia intends to submit to the Serbian Parliament a *General Law on the Prohibition of Discrimination* that had been drafted by experts of Institute for Comparative Law in Belgrade. The draft contains provision on prohibition of discrimination against people with disabilities. The Law should enter parliamentary procedure by the end of 2004.

The Ministry of Labour, Employment and Social Affairs of Serbia intends to submit to Parliament a Law on Prohibition of Discrimination against People with disabilities. The law had been drafted by an expert team from the Institute for the Advancement of Legal Studies in Belgrade in 2003. The team included people with disabilities. The institute's draft was open to public debate in 2004 after which a second draft was submitted to the working group established by the Ministry of Labour, Employment and Social Affairs.

⁶³ "Official Gazette of the Republic of Serbia", No. 25/96.

⁶⁴ These companies are not cost-effective and they are owned by the State. The process of privatisation will not be done for them because the private sector is not interested in protected workshops.

⁶⁵ "Official Gazette of the Republic of Serbia", No. 18/97.

⁶⁶ "Official Gazette of the Republic of Serbia", No. 47/03.

⁶⁷ See the publication from the Centre for Policy Studies and Handicap International, "People with Disabilities and the Environment", (Belgrade: Centre for Policy Studies and Handicap International, 2001).

⁶⁸ "Official Gazette of the Republic of Serbia", No. 43/03.

THE REPUBLIC OF MONTENEGRO

GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES IN MONTENEGRO:

In Montenegro, the protection of people with disabilities is provided through various systems, such as: pension and disability insurance, health care and insurance, employment and vocational training, education, social welfare, urbanism and planning, protection of war veterans and civil victims of war. The Constitution of Montenegro guarantees special protection to people with disabilities (article 56). The social security system in Montenegro includes: pension and disability insurance, health insurance and insurance in case of unemployment.

SOCIAL WELFARE

a) **Main legal documents** - Concerning social welfare, the Republic of Montenegro has a complex system, which covers social payments, family protection, childcare, care for pregnant women and single mothers, care for the elderly and people with disabilities. The *Law on Social and Child Protection*⁶⁹ governs the system of social protection. It guarantees the various benefits in the area of social welfare and also regulates the establishment of social welfare institutions, as well as health protection for citizens that don't obtain it through other systems and sources. Social welfare issues in Montenegro are also partially regulated by number of ordinances, regulations as well as the *Law on the Red Cross of Montenegro*⁷⁰.

b) **Beneficiaries** - According to the *Law on Social and Child Protection*, social welfare beneficiaries are: individuals with complete incapacity to work (defined by the regulations on the pension and disability insurance); people able to take care of themselves due to a disability or illness; children and youth with disabilities or difficulties in development, as well as some other categories of citizens who require social protection.

c) **Rights** - The right to social benefits is regulated by the *Law on Social and Child Protection* and includes: financial assistance for the family (MOP), allowance for care and assistance of another person, allowance for vocational training, home care and assistance, day care, placement in a social institution or foster family, social welfare services, equipment for the beneficiary for placement in a social institution or foster family, one-time financial allowance, health care (for individuals who cannot realise that right from on other legal grounds) and funeral costs. The law also prescribes for various forms of benefits related to child rearing and specific social support to children.

d) **Financing** - Social welfare benefits and the entire system of social welfare are financed from the republican budget.

HEALTH CARE AND INSURANCE

a) **Main legal documents** - The *Law on Health Care and the Law on Health Insurance* regulate the health care system in Montenegro. Health care and rehabilitation for people with physical and intellectual disabilities is specifically included in primary health care. The *Law on Health Care* prescribes also some of the ethic postulates of health care provisions among which is the right of the patient to refuse treatment. The law prescribes that doctors are competent to commit persons with psychiatric conditions into institutions and prescribe mandatory treatment if the above mentioned individuals constitute a danger to themselves and others. Health care and insurance in Montenegro is partially regulated by a number of regulations, ordinances as well as the *Law on Social and Child Protection*.

b) **Rights** - The *Law on Health Insurance* regulates rights from the health insurance of employees and other citizens, included in compulsory health insurance. Rights from health insurance include: health care, salary compensation during the period when the person was temporarily unable to work, travel expenses and compensation related to health care. Health care among others includes the right to medical treatment, rehabilitation and orthopedic aids. Insured persons are provided with general and specialised medical rehabilitation. People with disabilities are among those who should be given priority for health care under the law.

c) **Financing** - The most important source of health care financing is the publicly owned compulsory health care insurance fund called the Health Insurance Fund (HIF). Additional sources are the republican budget (which is paying for the care services of uninsured citizens) and individual financial contributions.

PENSION AND DISABILITY INSURANCE

a) **Main legal documents** - The *Law on Pension and Disability Insurance*⁷¹ states that insured persons are eligible to exercise their rights from compulsory pension and disability insurance in the case of old age, disability, death and physical injury. Compulsory insurance on the basis of capitalised savings and voluntary insurance shall be regulated by separate laws.

b) **Rights** - The rights from pension and disability insurance include:

- In the case of old age - the right to old age pension,
- In the case of disability - the right to disability pension,

⁶⁹ "Official Gazette of the Republic of Montenegro", No. 45/93, 27/94, 16/95, 44/01, 43/03.

⁷⁰ "Official Gazette of the Republic of Montenegro", No. 39/91, 48/91, 17/92, 27/94.

⁷¹ "Official Gazette of the Republic of Montenegro ", No. 54/03.

- In the case of death: a) the right to family pension and b) the right to compensation for burial expenses,
 - In the case of physical injury caused by an accident at work or occupational disease - the right to compensation for the physical injury.
- c) **Assessment** - Insured persons exercise their rights through the Pension and Disability Fund. Request for the right to disability pension should be submitted to this Fund. In order to decide on a person's right to pension and disability insurance, and to confirm the existence of disability, physical injury, cause of disability and physical injury, the Pension and Disability Fund uses the documentation, opinion and estimation of medical experts.
- d) **Financing** - The pension and disability insurance is provided by the Pension and Disability Fund which is a legal entity for the achievement of these rights and provision of allowances.

PROTECTION OF DISABLED VETERANS AND CIVIL VICTIMS OF WAR

- a) **Main legal documents** - The *Law on Protection of Combatants and Disabled Persons*⁷² regulates the rights of disabled veterans, families of soldiers who were killed and families of disabled veterans, civil victims and families of civil victims of the Balkan Wars, World War I and World War II as well as the conflicts that occurred in the '90s in a single act. This is a departure from previous legal practice when separate laws had been used to regulate rights of disabled veterans and civil victims of war.
- b) **Rights** of disabled veterans and civil victims of war under the *Law on Protection of Combatants and Disabled Persons* include: personal disability allowance, allowance for care and assistance by another person, orthopedic allowance, health care and other rights related to health care, free and privileged transport, family allowances, a monthly cash allowance, the right to orthopedic aids, the right to spa and climatic treatments, and compensation for burial expenses. Financial means for this protection come from the republican budget.

EDUCATION

- a) **Main legal documents** - The Education of children and youth with disabilities is regulated by the *General Law on Education, Law on Special Education*⁷³, the *Law on Pre- School Education, the Law on Primary Education, the Law on Secondary Education, the Law on Education of Adults, the Law on Professional Training, the Law on Higher Education* and a number of regulations. The *General Law* prescribes that everyone has the right to access to education and it prohibits discrimination on the grounds of race, sex, gender, religion, language, national or social origin and other statuses, but fails to explicitly mention disability. It stipulates that education for children with special educational needs, including children with developmental difficulties as well as talented children. Children with developmental difficulties can attend regular classes if a Commission for Categorisation determines that they are capable to do so. The *Law on Pre- School Education* regulates the education of children with special needs and provides opportunities for individualised work in smaller groups. The Education of children and youths with disabilities is further regulated by the *Law on Special Education* which sets segregated special education as the norm and integrated education as an exception.
- b) **Commissions for Categorisation** - A child with difficulties in development is included in the system of education according to the decision made by the Commission for Categorisation. Categorisation of children is still done according to the *Decision on Criteria for Categorisation of Children with Difficulties in Development*⁷⁴ from 1979 which is based on a medical approach.
- c) **University education** - The *Law on Higher Education* states that everyone shall have access to higher education under equal conditions (article 6) and prohibits discrimination on the grounds of disability (article 7). The government of Montenegro is responsible for securing conditions for equal access to higher education for students with disabilities (article 9).

EMPLOYMENT

- a) **Main legal documents** - The main legal acts are the *Law on Employment of the Republic of Montenegro*⁷⁵ and the *Labour Law of the Republic of Montenegro*⁷⁶. According to the Law on Employment, the Institute for Employment of Montenegro, a publicly directed institution, creates conditions for employment of people with disabilities. It can transfer functions pertaining to the employment of people with disabilities to licensed agencies. The institute will direct unemployed individuals to various job opportunities and people with disabilities are among the categories of unemployed people who will receive priority treatment.

The Labour Law stipulates the rights, obligations and responsibilities related to work. A person with disabilities who is capable to perform particular tasks is entitled to a specific labour agreement. Working openings for people with disabilities do not have to be advertised publicly. Council of employees, among other functions, deals with the working conditions for people with disabilities. People with disabilities that undergo vocational training and receive additional qualifications can be transferred from one working place to another suitable one by his/her employer.

⁷² " Official Gazette of the Republic of Montenegro ", No. 69/03

⁷³ " Official Gazette of the Republic of Montenegro ", No. 56/92.

⁷⁴ " Official Gazette of the Republic of Montenegro ", No. 2/79

⁷⁵ " Official Gazette of the Republic of Montenegro ", No. 05/02.

⁷⁶ " Official Gazette of the Republic of Montenegro ", No. 43/03

ACCESSIBILITY

Access to public facilities by people with disabilities is regulated by the *Law on the Construction of Facilities*⁷⁷. It stipulates that new public facilities must be accessible to people with disabilities (article 11). Residential complexes that contain 10 or more apartments must contain accessible general facilities and at least 1 / 10 of the flats must be accessible. The law regulates the technical conditions and control of planning for facilities in public use including sanctions for violations of the law. However, the law does not specifically refer to accessibility standards in further articles of the text.

ANTI-DISCRIMINATION

The Parliaments of Serbia, Montenegro and Federal Republic of Yugoslavia adopted the Constitutional Charter and the Minority and Human Rights Charter of Serbia and Montenegro in early 2003. Clause 3 of article 3 of the Minority and Human Rights Charter of Serbia and Montenegro prohibits discrimination on the basis of physical and intellectual disabilities. There is no specific anti-discrimination law in Montenegro that would further elaborate provisions of the Minority and Human Rights Charter.

⁷⁷ " Official Gazette of the Republic of Montenegro ", No. 55/00

DISABILITY LEGISLATIVE OVERVIEW

THE UN ADMINISTERED PROVINCE OF KOSOVO

GENERAL FACTS ABOUT THE UN ADMINISTERED PROVINCE OF KOSOVO

People⁷⁸

Population	1,900,000
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Government

Capital	Pristina
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Economy⁷⁹

GDP, million € (2004)	1,641
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GDP real growth rate (2004)	3,9%
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GDP - per capita in € (2004)	705
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Unemployment rate (2004)	44%
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People that live below the poverty line (2004)	47%
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Health

Total health expenditure per capita (Intl \$, 2001):	NA
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Total health expenditure as % of GDP (2001):	NA
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SPECIFIC POLITICAL SITUATION IN THE UN ADMINISTERED PROVINCE OF KOSOVO

After the NATO bombing campaign against the former Republic of Yugoslavia in March 1999, Kosovo remains a province of Serbia and Montenegro, but has been under the administration of the United Nations Mission in Kosovo (UNMIK). UNMIK was created in June 1999, when the Security Council in Resolution 1244 authorised the Secretary-General to establish an interim civilian administration led by the United Nations in the province of Kosovo. UNMIK performs essential administrative functions and services covering areas such as, health and education, banking and finance, post and telecommunications and law and order. In January 2000, the Joint Interim Administrative Departments were created. In May 2001, the new Constitutional Framework of Kosovo was adopted and elections were held on 17 November 2001 to form the Kosovo Provisional Assembly as mandated by UNMIK⁸⁰.

GENERAL POLICY TOWARDS PEOPLE WITH DISABILITIES

The UN administered province of Kosovo is still missing a legitimate legislative infrastructure which would regulate issues relating to people with disabilities. Until now, the Kosovo Assembly has approved few regulations which, in a decisive way, regulate issues concerning people with disabilities. They include: *The Regulation on Primary and Secondary Education, the Regulation on Social Assistance Scheme, the Regulation on Basic Pension and the Regulation on Disability Pension* (which was implemented in January 2004). Despite these approved regulations, Kosovo lacks a proper system for social services aimed at providing efficient and better social services for people with disabilities.

SOCIAL WELFARE

a) **Main legal documents** - The *Law on the Social Assistance Scheme in Kosovo* provides a social protection network within the broader context of the social protection system in Kosovo alleviating poverty by providing Social Assistance to poor and vulnerable families in need. This Law established the Social Assistance Scheme of Kosovo in order to protect vulnerable families. The Department of Social Welfare is the unit that manages Social Welfare programmes including pensions, social assistance, social care and social institutions. Within this department the Social Welfare Payment Division is placed which is in charge of the overall management of the Basic Pension, the War Invalids/next of Kin scheme, the Social Assistance Scheme and the Disability Pension. The Commissions for the Social Assistance scheme are based on the local level.

b) **Beneficiaries** - The *Law on the Social Assistance Scheme* includes all persons 18 years or older who have permanent and severe disabilities rendering them unable to work for remuneration.

c) **Rights** - Financial support is the main benefit that persons with disability can realise from this law. Families in which all family members are either, 65 years or older or people with disabilities at the time when they are going to benefit from any future scheme of the Disability Pension, funded either by the Kosovo Consolidated Budget or if they are being paid under Regulation 2000/66, which governs the scheme of "*Benefits for the war invalids of Kosovo and for the next of kin of those who died as a result of the armed conflict in Kosovo*", are given an individual entitlement.

⁷⁸ UNDP Human Development Report for Kosovo 2004

⁷⁹ UNDP Early Warning Report, Report No. 6, January - April 2004

⁸⁰ Official website of UNMIK available at: www.unmikonline.org,

d) **Financing** - The Ministry of Labour and Social Welfare and the Ministry of Finance and Economy may, in accordance with the *Law on Public Financial Management and Accountability* and within the proposed overall budget, include one-time payments to families who are eligible for Social Assistance.

HEALTH CARE AND INSURANCE

a) **Main legal documents** - The *Law on Health* regulates medical protection of the population. This is a draft law, which has been approved by the Kosovo Assembly but it is still not signed by the Special Representative of UN General Secretary in Kosovo. This means that the law is still not valid and the medical protection of the population is not regulated.

b) **Rights** - Currently, there is no law regulating health insurance and no system of health insurance exists.

c) **Financing** - As there is no health insurance system, the Kosovo Health budget directly covers the expenditures of the Pristina Hospital, regional hospitals, and the salaries of health professionals working within Primary Health Care⁸¹.

PENSION AND DISABILITY INSURANCE

a) **Main legal documents** - In December 2003, the *Law on Disability Pension* was approved by the Kosovo Assembly and signed by the former UN representative for Kosovo, Mr. Harri Holkeri. The legislation was implemented in January 2004. However, there is still no law considering disability insurance. The Pension Fund is placed under the Ministry of Labour and Social Welfare.

b) **Rights** - Disability pension is available for any person living in the UN administered province of Kosovo, between the ages of 18 and 65 years who is 100% permanently disabled and incapable of any type of occupational activity. The pension is paid monthly to individuals (not to their families or dependants). The applicant will have to attend a physical medical examination by a commission composed of doctors, which will be established by the Ministry of Labour and Social Welfare. The disability pension is 75 euros per month.

c) **Assessment** - The present system of having a separate medical commission for each social scheme will be replaced by a single commission for all benefit schemes. A priority for the Social Welfare Payment Division is to standardise the process of disability assessment across all benefit schemes. This will include standardised definitions of disability at each level, standard methodology used by doctor's commissions, and standard assessment and reporting tools.

PROTECTION OF DISABLED VETERANS

a) **Main legal documents** include: *Regulation No. 2000/66 on the Benefits for War Invalids of Kosovo and the Family Members of those who died in Armed Conflict in Kosovo*⁸².

b) **Beneficiaries** - The beneficiaries of War Invalid Scheme are people with disabilities and family members of people who died in the armed conflict. There are two categories of disability based on percentages: 40 - 69% and 70 - 100%.

c) **Rights** - Benefits under the present regulation include: financial payments for war invalids; free access to medical care provided in government health centres and rehabilitation centres in Kosovo for war invalids and their family members; exemption from sales tax, excise tax and customs duties on vehicles adapted for the specific disabilities of the war invalid; financial payments for family members of those who died as a result of the armed conflict in Kosovo.

d) **Assessment** - The commissions for the War Invalid Scheme are based at the central level and are composed of medical professionals in which they assess one's level of disability based on the two categories. These commissions were established by the Administrative Department of Health and Social Welfare. The commissions for assessing the Social Assistance Scheme are mixed meaning they are composed of both medical and social service professionals.

PROTECTION OF CIVIL VICTIMS OF WAR

The protection of civil victims of war is integrated into the social welfare system.

EDUCATION

According to *Law No. 2002/19 on Primary and Secondary Education in Kosovo* adopted in October 2002, primary and secondary education should be accessible to all citizens of the UN administered province of Kosovo and no child shall be denied the right to education. In addition, *Law No. 2003/14 on Higher Education* adopted in May 2003 guarantees the right to higher education for all the citizens of the UN administered province of Kosovo⁸³.

⁸¹ For more information see Pascal Granier, "Physical Rehabilitation Services in South East Europe", (Belgrade: Handicap International, 2004).

⁸² UNMIK/REG/2000/66, from 21 December 2000

⁸³ "Higher education ... in Kosovo shall be accessible to all persons in the territory of Kosovo, or by distance learning within or outside Kosovo in any location, without direct or indirect discrimination on any actual or presumed ground such as sex, race, sexual orientation, physical, or other impairment..." (Law on Higher Education, section 3, article 3.1)

a) **Main legal documents** - Special education is decentralised both in terms of responsibility and financing. The issue on special education in the UN administered province of Kosovo is regulated in Chapter VII (Sections 35 - 40) of the *Law on Primary and Secondary Education in Kosovo*⁸⁴.

b) **Commissions for Categorisation** - Assessment is provided by a group of experts based in the municipality. The assessment determines whether the pupil needs special education and what kind of tuition should be provided. The expert assessment shall consider and determine the following issues: whether the pupil can attend mainstream school, the pupil's learning difficulties and other special conditions of importance regarding their education, realistic educational objectives for the pupil, what kind of education is appropriate, and whether it is possible to provide support for the child according to their impairment within mainstream educational provisions. The *Law on Primary and Secondary Education* stipulates the establishment of Commissions for Categorisation at the municipal level but they have not been established yet.

c) **Special schools and special classes** - There are 7 special schools in the UN administered province of Kosovo including, special schools for blind children and children with visual impairments, schools for deaf children and those with hearing impairments and special schools for children with intellectual disabilities. Concerning inclusive education, there are approximately 40 special classes throughout the UN administered province of Kosovo operating as a part of mainstream schools. For the moment, there are no school assistants and the only supportive mechanism for inclusive education is the establishment of a group of trainers who attended a 2 year training course on special education.

EMPLOYMENT

a) **Main legal documents** - Within the UN administered province of Kosovo, there is only one law called *Regulation No. 2001/27 on Essential Labour Law in Kosovo* adopted in October 2001, which regulates employment including the employment relationship under which an employee works. Section two of this law concerns the prohibition of discrimination in employment and occupation including on the grounds of disability⁸⁵.

b) **Vocational training and rehabilitation** - The Department of Labor and Social Welfare has opened some centers for vocational training. These centers offer training for various professions for people with disabilities as well according to their abilities and the needs on the labor market. For the moment, Employment Offices do not have any special department for employment of people with disabilities but they strongly support them through Centres for Vocational Trainings.

Vocational Training Division is responsible for training jobseekers for the labour market. All people with disabilities who are of work age, have the right to attend vocational rehabilitation provided by centres for vocational training and get employed if they get such possibility.

c) **Sheltered workshops** - there are no sheltered workshops in Kosovo.

ACCESSIBILITY

There is no specific law regulating this issue.

ANTI-DISCRIMINATION

Concerning anti-discrimination in general, the Assembly of Kosovo adopted *Law No. 2004/3 on Antidiscrimination* in February 2004. The purpose of this law is to prevent and combat discrimination and promote equality by applying the principle of equal treatment of all citizens of the UN administered province of Kosovo. Under article 2 of the legislation it states, "The principle of equal treatment shall mean that there shall be no direct or indirect discrimination against any person or persons, based on sex, gender, age, marital status, language, mental or physical disability[...]".

⁸⁴ "Pupils who either do not or are unable to attend mainstream education, have the right to special education and it should be a duty of a municipality to provide that in accordance with the provisions of this law and within the framework and limits of the municipal budget" (*Law on Primary and Secondary Education in Kosovo*, section 7, article 35.1)

⁸⁵ "Discrimination against a disabled person, whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized natural or mental impairment, is prohibited." (*Regulation on Essential Labor Law in Kosovo*, section 2, article 2.4)

DIRECTORY of good practices presented in the report

NAME OF SERVICE	CONTACT DETAILS	TYPE OF SERVICES PROVIDED
National Centre for Growth Development and Rehabilitation, Tirana	<p>Donika Muzi, Director Rr. Haxhi Sferri i Kombinet Tirana Albania Tel: +355 4 351 074 / 351 893 Fax: +355 4 351 974 E-mail: dkmzh@albonet.net</p>	<p>Public institution providing diagnostic assessments and support to children with developmental difficulties 0-6 years old through following activities:</p> <ul style="list-style-type: none"> - Different rehabilitation therapies such as physiotherapy, occupational therapy, speech therapy, psychological support, etc. - Training and counselling to parents according to a "rooming-in" model with the children, <ul style="list-style-type: none"> - home visits to families at risk, - Training of other health professionals in early intervention and rehabilitation and interdisciplinary team work, - Special seating device production.
DUGA, Sarajevo	<p>Anka Tzethoavlj, President Zmajeva ul. Bosna, 36 Sarajevo Bosnia and Herzegovina Tel: + 387-33-215 117 / 670 249 E-mail: info_duga@yahoo.com</p>	<p>NGO working with support to children and youth with social and psychological difficulties, as well as with disabilities through following activities:</p> <ul style="list-style-type: none"> - Discussion groups and round tables, - Support to teachers and pedagogues, - Group and individual counselling for youth, - Lobbying for educational reform in B.H.
Information Centre Lotos, Tuzla	<p>Saad Zehirovic, Director Sr. M. Umrogarcevic 3 Tuzla Bosnia and Herzegovina Tel: +387-35-251245 E-mail: lotos@otih.net.ba</p>	<p>NGO for people with disabilities that aims to create a democratic civil society in which disability issues will be considered as a Human Rights issue and people with disabilities will have no barrier to experience education, employment, livelihood and freedom of movement through following:</p> <ul style="list-style-type: none"> - Information centre for people with disabilities, - Employment training centre, <ul style="list-style-type: none"> - Day Care centre for children with disabilities (Koraci Bude), - Lobbying and advocacy activities at local and regional levels.
Centre for Independent Living, Sofia	<p>Kenka Ivanova Paroyatova, Director 17, Str. September Street Sofia 1000 Bulgaria Tel: +359-2-9833117 E-mail: cil@cil-bg.org website: www.cil-bg.org</p>	<p>A non-profit organisation of people with disabilities that supports people with disabilities to achieve equal opportunities for participation in community life. The main activities include:</p> <ul style="list-style-type: none"> - Advocacy and lobbying for equal opportunities of people with disabilities, - Networking (nationally, regionally and international), - Publications and dissemination of information and research on disability issues, - Information, consultations and trainings.

NAME OF SERVICE	CONTACT DETAILS	TYPE OF SERVICES PROVIDED
Karin Dom Foundation, Varna	Roumiana Hristova, President Sveti Nikola P.O.Box 104 9010 Varna Bulgaria Tel: +359-52-302 517 Fax: +359-52-302 515 E-mail: karindom@bta.bg	NCC that provides community-based services to children with disabilities to promote their integration into community through following activities: - Daily centre for rehabilitation, socialisation, counselling, education and early intervention, - Support to families of children with disabilities, - Support to inclusive education, - Training and resource centre.
Association for Promoting Inclusion, Zagreb	Burka Teodorovic, President Mleiweisova St. 15 10 000 Zagreb Croatia Tel: +385-01-251 68 28 E-mail: burka.teodorovic@zaj.hr	NCC that promotes the full participation of people with intellectual disabilities in society through a set of community-based services: - Prevention of institutionalisation and programmes for de-institutionalisation, - Foster family programmes, - Supported employment, - Self-advocacy, - Creative workshops, - Education and training service, etc.
Handikos, Pristina	Halki Fortzi, President Dardania 47 Lam. D2 38 000 Pristina UN administered province of Kosovo Tel: +381-38-548 326 / 550834 E-mail: handikos@ipk.org	EPO that promotes and supports the full inclusion and participation in society of people with disabilities through following activities: - Political development and self-representation, - Service provision through 10 community centres (based on CBR) for children with disabilities, - Lobby and advocacy for employment reforms and other legislative reforms.
Polio plus, Movement against Disability, Skopje	Zeljko Savicki, President 51, Metropoli, Tanasie Gojganev Bld. 29 1000 Skopje Republic of Macedonia Tel: +389 (02) 3298327 Fax: +389 (02) 2390329 E-mail: polioplus@polioplus.org.mk website: www.polioplus.org.mk	EPO that focus on self-advocacy and awareness raising on disability rights through following core strategies: - Legislative / policy changes, - Employment through Education, - Awareness raising / civic education, - Vulkan magazine.
PORAKA, Republic Centre for Helping Persons with Intellectual Disability, Skopje	Cedomir Trajkovski, President Orca Nikolev Bld. 122, 1000 Skopje, Republic of Macedonia Tel: +389-2-32 96 961 Fax: +389-2-32 96 960 e-mail: poraka@mal.com.mk website: www.poraka.org.mk	EPO / Parent Association that represents the rights and interest of persons with intellectual disabilities through following activities: - Improving policy at national level, - Coordination of local branches, - Establish a network of community-based services, - Communication and exchange of information on national and international level.
Aurora Day Care centre / ASCHF-R, Bucharest	Diana Chiriacescu, Director 89 Teles Voda Street Sector 2 Bucharest Romania Tel: 40-01-320 26 74 / 314 5679 E-mail: dcaurora@dn.ro	NCC and service provider offering services to children with neuro-motor disabilities through: - Educational Day Care centre, - Vocational training centre, - Resource and information centre for parents and professionals.

NAME OF SERVICE	CONTACT DETAILS	TYPE OF SERVICES PROVIDED
Pentru Voi Foundation, Timisoara	Lilla Onu, Director Str. Tomi Slavici Nr. 47 JUGU25 Timisoara Romania Tel: +40-256-228 067 Fax: +40-256-228 473 E-mail: pentruvoi@pentruvoi.ro website: www.pentruvoi.ro	NGO service provider that provides community based support services to persons with intellectual disabilities through following activities: - Day Services (workshops, employment, day care), - Residential services, - Community support (counselling, leisure activities), - Advocacy and self-advocacy, - Training providers to other NGOs and professionals working with persons with disabilities.
Motivation Foundation Romania, Bucharest	Christian Ispas, President Bos. Alexandrii no. 478, com. Bucuresti, Ilfov county Romania Tel: +40-21-448 11 07 / 493 21 42 E-mail: cispas@motivation.ro, romanian@motivation.ro website: www.motivation.ro	NGO that promotes the independent living and quality of life of people with disabilities, focusing on wheelchair users through following activities: - Counselling and psychological support within their community centre, - Active Rehabilitation program, - Information and campaigns, - De-institutionalisation project for children with disabilities, - Accessible summer camps for improving independency for wheelchair users.
Centre for Independent Living, Belgrade	Gordana Rajkovic, President Sr. Radomira Vujovic 5 11000 Belgrade Serbia and Montenegro Tel: +381 11 350 55 09 E-mail: c@srbijski@digicool.yu	DPO that promotes the philosophy of Independent Living through following activities: - Promotion and information on Independent Living, - Lobbying and advocacy activities for improving legislation and accessibility, - Introducing user managed Personal Assistance service in Serbia and Montenegro.
Association of students with disabilities, Belgrade	Goran Pavlovic, President Vojvode Stepa 33 11000 Belgrade Serbia and Montenegro Tel: +381 11 33 561 131/1517 07 E-mail: office@edsyu.org website: www.edsyu.org	DPO that promotes the rights of young people and students with disability to achieve higher education through following activities: - Counselling and psychological support to students at university, - Lobbying and advocacy to improve the quality of life of young people with disabilities, - Information and communication regarding disability (bulletin "Bus 1").



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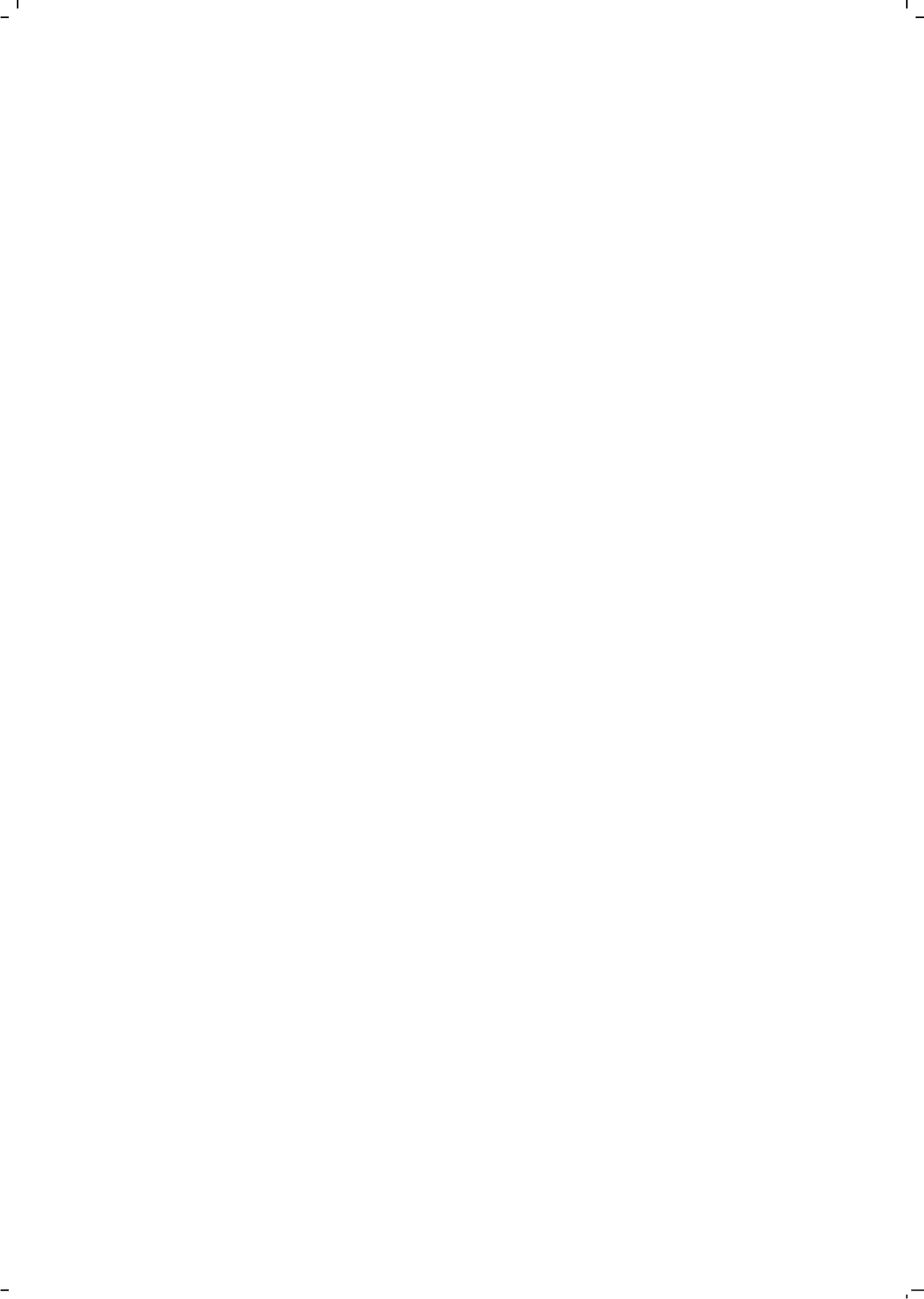
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ANNEXES

**ANNEX 1 - UN STANDARD RULES ON THE EQUALIZATION OF
OPPORTUNITIES FOR PERSONS WITH DISABILITIES**

ANNEX 2 - AGENDA 22

ANNEX 1

UN STANDARD RULES ON THE EQUALIZATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES **General Assembly resolution 48/96 of 20 December 1993**

The General Assembly,

Recalling Economic and Social Council resolution 1990/26 of 24 May 1990, in which the Council authorized the Commission for Social Development to consider, at its thirty second session, the establishment of an ad hoc open-ended working group of government experts, funded by voluntary contributions, to elaborate standard rules on the equalization of opportunities for disabled children, youth and adults, in close collaboration with the specialized agencies, other intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons, and requested the Commission, should it establish such a working group, to finalize the text of those rules for consideration by the Council in 1993 and for submission to the General Assembly at its forty-eighth session, Also recalling that in its resolution 32/2 of 20 February 1991 1/ the Commission for Social Development decided to establish an ad hoc open-ended working group of government experts in accordance with Economic and Social Council resolution 1990/26,

Noting with appreciation the participation of many States, specialized agencies, intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons, in the deliberations of the working group,

Also noting with appreciation the generous financial contributions of Member States to the working group,

Welcoming the fact that the working group was able to fulfil its mandate within three sessions of five working days each,

Acknowledging with appreciation the report of the ad hoc open-ended working group to elaborate standard rules on the equalization of opportunities for persons with disabilities ,

Taking note of the discussion in the Commission for Social Development at its thirty-third session on the draft standard rules contained in the report of the working group,

1. Adopts the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, set forth in the annex to the present resolution;
2. Requests Member States to apply the Rules in developing national disability programmes;
3. Urges Member States to meet the requests of the Special Rapporteur for information on the implementation of the Rules;
4. Requests the Secretary-General to promote the implementation of the Rules and to report thereon to the General Assembly at its fiftieth session;
5. Urges Member States to support, financially and otherwise, the implementation of the Rules.

INTRODUCTION

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IV. MONITORING MECHANISM

INTRODUCTION

Background and current needs

1. There are persons with disabilities in all parts of the world and at all levels in every society. The number of persons with disabilities in the world is large and is growing.
2. Both the causes and the consequences of disability vary throughout the world. Those variations are the result of different socio-economic circumstances and of the different provisions that States make for the well-being of their citizens.
3. Present disability policy is the result of developments over the past 200 years. In many ways it reflects the general living conditions and social and economic policies of different times. In the disability field, however, there are also many specific circumstances that have influenced the living conditions of persons with disabilities. Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development.
4. Over the years, disability policy developed from elementary care at institutions to education for children with disabilities and rehabilitation for persons who became disabled during adult life. Through education and rehabilitation, persons with disabilities became more active and a driving force in the further development of disability policy. Organizations of persons with disabilities, their families and advocates were formed, which advocated better conditions for persons with disabilities. After the Second World War the concepts of integration and normalization were introduced, which reflected a growing awareness of the capabilities of persons with disabilities.
5. Towards the end of the 1960s organizations of persons with disabilities in some countries started to formulate a new concept of disability. That new concept indicated the close connection between the limitation experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. At the same time the problems of disability in developing countries were more and more highlighted. In some of those countries the percentage of the population with disabilities was estimated to be very high and, for the most part, persons with disabilities were extremely poor.

Previous international action

6. The rights of persons with disabilities have been the subject of much attention in the United Nations and other international organizations over a long period of time. The most important outcome of the International Year of Disabled Persons, 1981, was the World Programme of Action concerning Disabled Persons, adopted by the General Assembly by its resolution 37/52 of 3 December 1982. The Year and the World Programme of Action provided a strong impetus for progress in the field. They both emphasized the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. There also, for the first time, handicap was defined as a function of the relationship between persons with disabilities and their environment.
7. The Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-Point of the United Nations Decade of Disabled Persons was held at Stockholm in 1987. It was suggested at the Meeting that a guiding philosophy should be developed to indicate the priorities for action in the years ahead. The basis of that philosophy should be the recognition of the rights of persons with disabilities.
8. Consequently, the Meeting recommended that the General Assembly convene a special conference to draft an international convention on the elimination of all forms of discrimination against persons with disabilities, to be ratified by States by the end of the Decade.
9. A draft outline of the convention was prepared by Italy and presented to the General Assembly at its forty-second session. Further presentations concerning a draft convention were made by Sweden at the forty-fourth session of the Assembly. However, on both occasions, no consensus could be reached on the suitability of such a convention. In the opinion of many representatives, existing human rights documents seemed to guarantee persons with disabilities the same rights as other persons.

Towards standard rules

10. Guided by the deliberations in the General Assembly, the Economic and Social Council, at its first regular session of 1990, finally agreed to concentrate on the elaboration of an international instrument of a different kind. By its resolution 1990/26 of 24 May 1990, the Council authorized the Commission for Social Development to consider, at its thirty-second session, the establishment of an ad hoc open-ended working group of government experts, funded by voluntary contributions, to elaborate standard rules on the equalization of opportunities for disabled children, youth and adults, in close collaboration with the specialized agencies, other intergovernmental bodies and non-governmental organizations, especially organizations of disabled persons. The Council also requested the Commission to finalize the text of those rules for consideration in 1993 and for submission to the General Assembly at its forty-eighth session.
11. The subsequent discussions in the Third Committee of the General Assembly at the forty-fifth session showed that there was wide support for the new initiative to elaborate standard rules on the equalization of opportunities for persons with disabilities.
12. At the thirty-second session of the Commission for Social Development, the initiative for standard rules

received the support of a large number of representatives and discussions led to the adoption of resolution 32/2 of 20 February 1991, in which the Commission decided to establish an ad hoc open-ended working group in accordance with Economic and Social Council resolution 1990/26.

Purpose and content of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

13. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities have been developed on the basis of the experience gained during the United Nations Decade of Disabled Persons (1983-1992). The International Bill of Human Rights, comprising the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights, the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women, as well as the World Programme of Action concerning Disabled Persons, constitute the political and moral foundation for the Rules.

14. Although the Rules are not compulsory, they can become international customary rules when they are applied by a great number of States with the intention of respecting a rule in international law. They imply a strong moral and political commitment on behalf of States to take action for the equalization of opportunities for persons with disabilities. Important principles for responsibility, action and cooperation are indicated. Areas of decisive importance for the quality of life and for the achievement of full participation and equality are pointed out. The Rules offer an instrument for policy-making and action to persons with disabilities and their organizations. They provide a basis for technical and economic cooperation among States, the United Nations and other international organizations.

15. The purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others. In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles. Persons with disabilities and their organizations should play an active role as partners in this process. The equalization of opportunities for persons with disabilities is an essential contribution in the general

and worldwide effort to mobilize human resources. Special attention may need to be directed towards groups such as women, children, the elderly, the poor, migrant workers, persons with dual or multiple disabilities, indigenous people and ethnic minorities. In addition, there are a large number of refugees with disabilities who have special needs requiring attention.

Fundamental concepts in disability policy

16. The concepts set out below appear throughout the Rules. They are essentially built on the concepts in the World Programme of Action concerning Disabled Persons. In some cases they reflect the development that has taken place during the United Nations Decade of Disabled Persons.

Disability and handicap

17. The term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

18. The term "handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms.

19. The use of the two terms "disability" and "handicap", as defined in paragraphs 17 and 18 above, should be seen in the light of modern disability history. During the 1970s there was a strong reaction among representatives of organizations of persons with disabilities and professionals in the field of disability against the terminology of the time. The terms "disability" and "handicap" were often used in an unclear and confusing way, which gave poor guidance for policy-making and for political action. The terminology reflected a medical and diagnostic approach, which ignored the imperfections and deficiencies of the surrounding society.

20. In 1980, the World Health Organization adopted an international classification of impairments, disabilities and handicaps, which suggested a more precise and at the same time relativistic approach. The International Classification of Impairments, Disabilities, and Handicaps makes a clear distinction between "impairment", "disability" and "handicap". It has been extensively used in areas such as rehabilitation, education, statistics, policy, legislation, demography, sociology, economics and anthropology. Some users have expressed concern that the Classification, in its definition of the term "handicap", may still be considered too medical and too centred on the individual, and may not adequately clarify the interaction between societal conditions or expectations and the abilities of the individual. Those concerns, and others expressed by users during the 12 years since its publication, will be addressed in forthcoming revisions of the Classification.

21. As a result of experience gained in the implementation of the World Programme of Action and of the general

discussion that took place during the United Nations Decade of Disabled Persons, there was a deepening of knowledge and extension of understanding concerning disability issues and the terminology used. Current terminology recognizes the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation).

Prevention

22. The term "prevention" means action aimed at preventing the occurrence of physical, intellectual, psychiatric or sensory impairments (primary prevention) or at preventing impairments from causing a permanent functional limitation or disability (secondary prevention). Prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunization campaigns against communicable diseases, measures to control endemic diseases, safety regulations, programmes for the prevention of accidents in different environments, including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Rehabilitation

23. The term "rehabilitation" refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.

Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.

Equalization of opportunities

24. The term "equalization of opportunities" means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities.

25. The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation.

26. Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.

27. As persons with disabilities achieve equal rights, they should also have equal obligations. As those rights are being achieved, societies should raise their expectations of persons with disabilities.

As part of the process of equal opportunities, provision should be made to assist persons with disabilities to assume their full responsibility as members of society.

PREAMBLE

States,

Mindful of the pledge made, under the Charter of the United Nations, to take joint and separate action in cooperation with the Organization to promote higher standards of living, full employment, and conditions of economic and social progress and development,

Reaffirming the commitment to human rights and fundamental freedoms, social justice and the dignity and worth of the human person proclaimed in the Charter,

Recalling in particular the international standards on human rights, which have been laid down in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights,

Underlining that those instruments proclaim that the rights recognized therein should be ensured equally to all individuals without discrimination,

Recalling the Convention on the Rights of the Child, which prohibits discrimination on the basis of disability and requires special measures to ensure the rights of children with disabilities, and the

International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families , which provides for some protective measures against disability,

Recalling also the provisions in the Convention on the Elimination of All Forms of Discrimination against Women to ensure the rights of girls and women with disabilities,

Having regard to the Declaration on the Rights of Disabled Persons , the Declaration on the Rights of Mentally Retarded Persons , the Declaration on Social Progress and Development , the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care and other relevant instruments adopted by the General Assembly,

Also having regard to the relevant conventions and recommendations adopted by the International Labour Organisation, with particular reference to participation in employment without discrimination for persons with

disabilities,

Mindful of the relevant recommendations and work of the United Nations Educational, Scientific and Cultural Organization, in particular the World Declaration on Education for All, the World Health Organization, the United Nations Children's Fund and other concerned organizations,

Having regard to the commitment made by States concerning the protection of the environment, Mindful of the devastation caused by armed conflict and deploring the use of scarce resources in the production of weapons, Recognizing that the World Programme of Action concerning Disabled Persons and the definition therein of equalization of opportunities represent earnest ambitions on the part of the international community to render those various international instruments and recommendations of practical and concrete significance,

Acknowledging that the objective of the United Nations Decade of Disabled Persons (1983-1992) to implement the World Programme of Action is still valid and requires urgent and continued action,

Recalling that the World Programme of Action is based on concepts that are equally valid in developing and industrialized countries,

Convinced that intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons with disabilities,

Re-emphasizing that persons with disabilities, and their parents, guardians, advocates and organizations, must be active partners with States in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights,

In pursuance of Economic and Social Council resolution 1990/26, and basing themselves on the specific measures required for the attainment by persons with disabilities of equality with others, enumerated in detail in the World Programme of Action,

Have adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities outlined below, in order:

- (a) To stress that all action in the field of disability presupposes adequate knowledge and experience of the conditions and special needs of persons with disabilities;
- (b) To emphasize that the process through which every aspect of societal organization is made accessible to all is a basic objective of socio-economic development;
- (c) To outline crucial aspects of social policies in the field of disability, including, as appropriate, the active encouragement of technical and economic cooperation;
- (d) To provide models for the political decision-making process required for the attainment of equal opportunities, bearing in mind the widely differing technical and economic levels, the fact that the process must reflect keen understanding of the cultural context within which it takes place and the crucial role of persons with disabilities in it;
- (e) To propose national mechanisms for close collaboration among States, the organs of the United Nations system, other intergovernmental bodies and organizations of persons with disabilities;
- (f) To propose an effective machinery for monitoring the process by which States seek to attain the equalization of opportunities for persons with disabilities.

I. PRECONDITIONS FOR EQUAL PARTICIPATION

Rule 1. Awareness-raising

States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

1. States should ensure that responsible authorities distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.
2. States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.
3. States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.
4. States should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.
5. States should invite persons with disabilities and their families and organizations to participate in public education programmes concerning disability matters.
6. States should encourage enterprises in the private sector to include disability issues in all aspects of their activity.
7. States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them.
8. Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities

of their own organizations.

9. Awareness-raising should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.

Rule 2. Medical care

States should ensure the provision of effective medical care to persons with disabilities.

1. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.

2. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.

3. States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

4. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.

5. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.

6. States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

Rule 3. Rehabilitation

States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

1. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.

2. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.

3. All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.

4. Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.

5. All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.

6. Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.

7. States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.

Rule 4. Support services

States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

1. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.

2. States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.

3. To achieve this, generally available technical know-how should be utilized. In States where high-technology industry is available, it should be fully utilized to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible.

Persons with disabilities themselves could be involved in the production of those devices.

4. States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.

5. In rehabilitation programmes for the provision of assistive devices and equipment, States should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness

of assistive devices and equipment.

6. States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.

7. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

II. TARGET AREAS FOR EQUAL PARTICIPATION

Rule 5. Accessibility

States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society. For persons with disabilities of any kind, States should (a) introduce programmes of action to make the physical environment accessible; and (b) undertake measures to provide access to information and communication.

(a) Access to the physical environment

1. States should initiate measures to remove the obstacles to participation in the physical environment. Such measures should be to develop standards and guidelines and to consider enacting legislation to ensure accessibility to various areas in society, such as housing, buildings, public transport services and other means of transportation, streets and other outdoor environments.

2. States should ensure that architects, construction engineers and others who are professionally involved in the design and construction of the physical environment have access to adequate information on disability policy and measures to achieve accessibility.

3. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process.

4. Organizations of persons with disabilities should be consulted when standards and norms for accessibility are being developed. They should also be involved locally from the initial planning stage when public construction projects are being designed, thus ensuring maximum accessibility.

(b) Access to information and communication

5. Persons with disabilities and, where appropriate, their families and advocates should have access to full information on diagnosis, rights and available services and programmes, at all stages. Such information should be presented in forms accessible to persons with disabilities.

6. States should develop strategies to make information services and documentation accessible for different groups of persons with disabilities. Braille, tape services, large print and other appropriate technologies should be used to provide access to written information and documentation for persons with visual impairments. Similarly, appropriate technologies should be used to provide access to spoken information for persons with auditory impairments or comprehension difficulties.

7. Consideration should be given to the use of sign language in the education of deaf children, in their families and communities. Sign language interpretation services should also be provided to facilitate the communication between deaf persons and others.

8. Consideration should also be given to the needs of people with other communication disabilities.

9. States should encourage the media, especially television, radio and newspapers, to make their services accessible.

10. States should ensure that new computerized information and service systems offered to the general public are either made initially accessible or are adapted to be made accessible to persons with disabilities.

11. Organizations of persons with disabilities should be consulted when measures to make information services accessible are being developed.

Rule 6. Education

States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system.

1. General educational authorities are responsible for the education of persons with disabilities in integrated settings. Education for persons with disabilities should form an integral part of national educational planning, curriculum development and school organization.

2. Education in mainstream schools presupposes the provision of interpreter and other appropriate support services. Adequate accessibility and support services, designed to meet the needs of persons with different disabilities, should be provided.

3. Parent groups and organizations of persons with disabilities should be involved in the education process at all levels.

4. In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.

5. Special attention should be given in the following areas:

- (a) Very young children with disabilities;
 - (b) Pre-school children with disabilities;
 - (c) Adults with disabilities, particularly women.
6. To accommodate educational provisions for persons with disabilities in the mainstream, States should:
- (a) Have a clearly stated policy, understood and accepted at the school level and by the wider community;
 - (b) Allow for curriculum flexibility, addition and adaptation;
 - (c) Provide for quality materials, ongoing teacher training and support teachers.
7. Integrated education and community-based programmes should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities. National community-based programmes should encourage communities to use and develop their resources to provide local education to persons with disabilities.
8. In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered. It should be aimed at preparing students for education in the general school system. The quality of such education should reflect the same standards and ambitions as general education and should be closely linked to it. At a minimum, students with disabilities should be afforded the same portion of educational resources as students without disabilities. States should aim for the gradual integration of special education services into mainstream education. It is acknowledged that in some instances special education may currently be considered to be the most appropriate form of education for some students with disabilities.
9. Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in schools for such persons or special classes and units in mainstream schools. At the initial stage, in particular, special attention needs to be focused on culturally sensitive instruction that will result in effective communication skills and maximum independence for people who are deaf or deaf/blind.

Rule 7. Employment

States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market.

1. Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment.
2. States should actively support the integration of persons with disabilities into open employment. This active support could occur through a variety of measures, such as vocational training, incentive-oriented quota schemes, reserved or designated employment, loans or grants for small business, exclusive contracts or priority production rights, tax concessions, contract compliance or other technical or financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities.
3. States' action programmes should include:
 - (a) Measures to design and adapt workplaces and work premises in such a way that they become accessible to persons with different disabilities;
 - (b) Support for the use of new technologies and the development and production of assistive devices, tools and equipment and measures to facilitate access to such devices and equipment for persons with disabilities to enable them to gain and maintain employment;
 - (c) Provision of appropriate training and placement and ongoing support such as personal assistance and interpreter services.
4. States should initiate and support public awareness-raising campaigns designed to overcome negative attitudes and prejudices concerning workers with disabilities.
5. In their capacity as employers, States should create favourable conditions for the employment of persons with disabilities in the public sector.
6. States, workers' organizations and employers should cooperate to ensure equitable recruitment and promotion policies, employment conditions, rates of pay, measures to improve the work environment in order to prevent injuries and impairments and measures for the rehabilitation of employees who have sustained employment-related injuries.
7. The aim should always be for persons with disabilities to obtain employment in the open labour market. For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative. It is important that the quality of such programmes be assessed in terms of their relevance and sufficiency in providing opportunities for persons with disabilities to gain employment in the labour market.
8. Measures should be taken to include persons with disabilities in training and employment programmes in the private and informal sectors.
9. States, workers' organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities, including flexible hours, part-time work, job-sharing, self-employment and attendant care for persons with disabilities.

Rule 8. Income maintenance and social security

States are responsible for the provision of social security and income maintenance for persons with disabilities.

1. States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities. States should ensure that the provision of support takes into account the costs frequently incurred by persons with disabilities and their families as a result of the disability.
2. In countries where social security, social insurance or other social welfare schemes exist or are being developed for the general population, States should ensure that such systems do not exclude or discriminate against persons with disabilities.
3. States should also ensure the provision of income support and social security protection to individuals who undertake the care of a person with a disability.
4. Social security systems should include incentives to restore the income-earning capacity of persons with disabilities. Such systems should provide or contribute to the organization, development and financing of vocational training. They should also assist with placement services.
5. Social security programmes should also provide incentives for persons with disabilities to seek employment in order to establish or re-establish their income-earning capacity.
6. Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve adequate and secure income.
7. States, in countries where social security is to a large extent provided by the private sector, should encourage local communities, welfare organizations and families to develop self-help measures and incentives for employment or employment-related activities for persons with disabilities.

Rule 9. Family life and personal integrity

States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

1. Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counselling of appropriate modules regarding disability and its effects on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.
2. Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.
3. States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society. The media should be encouraged to play an important role in removing such negative attitudes.
4. Persons with disabilities and their families need to be fully informed about taking precautions against sexual and other forms of abuse. Persons with disabilities are particularly vulnerable to abuse in the family, community or institutions and need to be educated on how to avoid the occurrence of abuse, recognize when abuse has occurred and report on such acts.

Rule 10. Culture

States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis.

1. States should ensure that persons with disabilities have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community, be they in urban or rural areas. Examples of such activities are dance, music, literature, theatre, plastic arts, painting and sculpture. Particularly in developing countries, emphasis should be placed on traditional and contemporary art forms, such as puppetry, recitation and story-telling.
2. States should promote the accessibility to and availability of places for cultural performances and services, such as theatres, museums, cinemas and libraries, to persons with disabilities.
3. States should initiate the development and use of special technical arrangements to make literature, films and theatre accessible to persons with disabilities.

Rule 11. Recreation and sports

States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports.

1. States should initiate measures to make places for recreation and sports, hotels, beaches, sports arenas,

gym halls, etc., accessible to persons with disabilities. Such measures should encompass support for staff in recreation and sports programmes, including projects to develop methods of accessibility, and participation, information and training programmes.

2. Tourist authorities, travel agencies, hotels, voluntary organizations and others involved in organizing recreational activities or travel opportunities should offer their services to all, taking into account the special needs of persons with disabilities. Suitable training should be provided to assist that process.

3. Sports organizations should be encouraged to develop opportunities for participation by persons with disabilities in sports activities. In some cases, accessibility measures could be enough to open up opportunities for participation. In other cases, special arrangements or special games would be needed. States should support the participation of persons with disabilities in national and international events.

4. Persons with disabilities participating in sports activities should have access to instruction and training of the same quality as other participants.

5. Organizers of sports and recreation should consult with organizations of persons with disabilities when developing their services for persons with disabilities.

Rule 12. Religion

States will encourage measures for equal participation by persons with disabilities in the religious life of their communities.

1. States should encourage, in consultation with religious authorities, measures to eliminate discrimination and make religious activities accessible to persons with disabilities.

2. States should encourage the distribution of information on disability matters to religious institutions and organizations. States should also encourage religious authorities to include information on disability policies in the training for religious professions, as well as in religious education programmes.

3. They should also encourage the accessibility of religious literature to persons with sensory impairments.

4. States and/or religious organizations should consult with organizations of persons with disabilities when developing measures for equal participation in religious activities.

III. IMPLEMENTATION MEASURES

Rule 13. Information and research

States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

1. States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.

2. States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities.

They should bear in mind the need to protect individual privacy and personal integrity.

3. States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.

4. States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.

5. States should facilitate the participation of persons with disabilities in data collection and research.

To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.

6. States should support the exchange of research findings and experiences.

7. States should take measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

Rule 14. Policy-making and planning

States will ensure that disability aspects are included in all relevant policy-making and national planning.

1. States should initiate and plan adequate policies for persons with disabilities at the national level, and stimulate and support action at regional and local levels.

2. States should involve organizations of persons with disabilities in all decision-making relating to plans and programmes concerning persons with disabilities or affecting their economic and social status.

3. The needs and concerns of persons with disabilities should be incorporated into general development plans and not be treated separately.

4. The ultimate responsibility of States for the situation of persons with disabilities does not relieve others of their responsibility. Anyone in charge of services, activities or the provision of information in society should be

encouraged to accept responsibility for making such programmes available to persons with disabilities.

5. States should facilitate the development by local communities of programmes and measures for persons with disabilities. One way of doing this could be to develop manuals or check-lists and provide training programmes for local staff.

Rule 15. Legislation

States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities.

1. National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable persons with disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other citizens. States must ensure that organizations of persons with disabilities are involved in the development of national legislation concerning the rights of persons with disabilities, as well as in the ongoing evaluation of that legislation.

2. Legislative action may be needed to remove conditions that may adversely affect the lives of persons with disabilities, including harassment and victimization. Any discriminatory provisions against persons with disabilities must be eliminated. National legislation should provide for appropriate sanctions in case of violations of the principles of non-discrimination.

3. National legislation concerning persons with disabilities may appear in two different forms. The rights and obligations may be incorporated in general legislation or contained in special legislation.

Special legislation for persons with disabilities may be established in several ways:

(a) By enacting separate legislation, dealing exclusively with disability matters;

(b) By including disability matters within legislation on particular topics;

(c) By mentioning persons with disabilities specifically in the texts that serve to interpret existing legislation.

A combination of those different approaches might be desirable. Affirmative action provisions may also be considered.

4. States may consider establishing formal statutory complaints mechanisms in order to protect the interests of persons with disabilities.

Rule 16. Economic policies

States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities.

1. States should include disability matters in the regular budgets of all national, regional and local government bodies.

2. States, non-governmental organizations and other interested bodies should interact to determine the most effective ways of supporting projects and measures relevant to persons with disabilities.

3. States should consider the use of economic measures (loans, tax exemptions, earmarked grants, special funds, and so on) to stimulate and support equal participation by persons with disabilities in society.

4. In many States it may be advisable to establish a disability development fund, which could support various pilot projects and self-help programmes at the grass-roots level.

Rule 17. Coordination of work

States are responsible for the establishment and strengthening of national coordinating committees, or similar bodies, to serve as a national focal point on disability matters.

1. The national coordinating committee or similar bodies should be permanent and based on legal as well as appropriate administrative regulation.

2. A combination of representatives of private and public organizations is most likely to achieve an intersectoral and multidisciplinary composition. Representatives could be drawn from concerned government ministries, organizations of persons with disabilities and non-governmental organizations.

3. Organizations of person with disabilities should have considerable influence in the national coordinating committee in order to ensure proper feedback of their concerns.

4. The national coordinating committee should be provided with sufficient autonomy and resources to fulfil its responsibilities in relation to its decision-making capacities. It should report to the highest governmental level.

Rule 18. Organizations of persons with disabilities

States should recognize the right of the organizations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters.

1. States should encourage and support economically and in other ways the formation and strengthening of organizations of persons with disabilities, family members and/or advocates. States should recognize that those organizations have a role to play in the development of disability policy.

2. States should establish ongoing communication with organizations of persons with disabilities and ensure their participation in the development of government policies.

3. The role of organizations of persons with disabilities could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with

disabilities, and to contribute to public awareness and to advocate change.

4. As instruments of self-help, organizations of persons with disabilities provide and promote opportunities for the development of skills in various fields, mutual support among members and information sharing.

5. Organizations of persons with disabilities could perform their advisory role in many different ways such as having permanent representation on boards of government-funded agencies, serving on public commissions and providing expert knowledge on different projects.

6. The advisory role of organizations of persons with disabilities should be ongoing in order to develop and deepen the exchange of views and information between the State and the organizations.

7. Organizations should be permanently represented on the national coordinating committee or similar bodies.

8. The role of local organizations of persons with disabilities should be developed and strengthened to ensure that they influence matters at the community level.

Rule 19. Personnel training

States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities.

1. States should ensure that all authorities providing services in the disability field give adequate training to their personnel.

2. In the training of professionals in the disability field, as well as in the provision of information on disability in general training programmes, the principle of full participation and equality should be appropriately reflected.

3. States should develop training programmes in consultation with organizations of persons with disabilities, and persons with disabilities should be involved as teachers, instructors or advisers in staff training programmes.

4. The training of community workers is of great strategic importance, particularly in developing countries. It should involve persons with disabilities and include the development of appropriate values, competence and technologies as well as skills which can be practised by persons with disabilities, their parents, families and members of the community.

Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Rules

States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalization of opportunities for persons with disabilities.

1. States should periodically and systematically evaluate national disability programmes and disseminate both the bases and the results of the evaluations.

2. States should develop and adopt terminology and criteria for the evaluation of disability-related programmes and services.

3. Such criteria and terminology should be developed in close cooperation with organizations of persons with disabilities from the earliest conceptual and planning stages.

4. States should participate in international cooperation in order to develop common standards for national evaluation in the disability field. States should encourage national coordinating committees to participate also.

5. The evaluation of various programmes in the disability field should be built in at the planning stage, so that the overall efficacy in fulfilling their policy objectives can be evaluated.

Rule 21. Technical and economic cooperation

States, both industrialized and developing, have the responsibility to cooperate in and take measures for the improvement of the living conditions of persons with disabilities in developing countries.

1. Measures to achieve the equalization of opportunities of persons with disabilities, including refugees with disabilities, should be integrated into general development programmes.

2. Such measures must be integrated into all forms of technical and economic cooperation, bilateral and multilateral, governmental and non-governmental. States should bring up disability issues in discussions on such cooperation with their counterparts.

3. When planning and reviewing programmes of technical and economic cooperation, special attention should be given to the effects of such programmes on the situation of persons with disabilities. It is of the utmost importance that persons with disabilities and their organizations are consulted on any development projects designed for persons with disabilities. They should be directly involved in the development, implementation and evaluation of such projects.

4. Priority areas for technical and economic cooperation should include:

(a) The development of human resources through the development of skills, abilities and potentials of persons with disabilities and the initiation of employment-generating activities for and of persons with disabilities;

(b) The development and dissemination of appropriate disability-related technologies and know-how.

5. States are also encouraged to support the formation and strengthening of organizations of persons with disabilities.

6. States should take measures to improve the knowledge of disability issues among staff involved at all levels in the administration of technical and economic cooperation programmes.

Rule 22. International cooperation

States will participate actively in international cooperation concerning policies for the equalization of opportunities for persons with disabilities.

1. Within the United Nations, the specialized agencies and other concerned intergovernmental organizations, States should participate in the development of disability policy.
2. Whenever appropriate, States should introduce disability aspects in general negotiations concerning standards, information exchange, development programmes, etc.
3. States should encourage and support the exchange of knowledge and experience among:
 - (a) Non-governmental organizations concerned with disability issues;
 - (b) Research institutions and individual researchers involved in disability issues;
 - (c) Representatives of field programmes and of professional groups in the disability field;
 - (d) Organizations of persons with disabilities;
 - (e) National coordinating committees.
4. States should ensure that the United Nations and the specialized agencies, as well as all intergovernmental and interparliamentary bodies, at global and regional levels, include in their work the global and regional organizations of persons with disabilities.

IV. MONITORING MECHANISM

1. The purpose of a monitoring mechanism is to further the effective implementation of the Rules. It will assist each State in assessing its level of implementation of the Rules and in measuring its progress. The monitoring should identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules. The monitoring mechanism will recognize the economic, social and cultural features existing in individual States. An important element should also be the provision of advisory services and the exchange of experience and information between States.
2. The Rules shall be monitored within the framework of the sessions of the Commission for Social Development. A Special Rapporteur with relevant and extensive experience in disability issues and international organizations shall be appointed, if necessary, funded by extra-budgetary resources, for three years to monitor the implementation of the Rules.
3. International organizations of persons with disabilities having consultative status with the Economic and Social Council and organizations representing persons with disabilities who have not yet formed their own organizations should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority, taking into account the different kinds of disabilities and necessary equitable geographical distribution, to be consulted by the Special Rapporteur and, when appropriate, by the Secretariat.
4. The panel of experts will be encouraged by the Special Rapporteur to review, advise and provide feedback and suggestions on the promotion, implementation and monitoring of the Rules.
5. The Special Rapporteur shall send a set of questions to States, entities within the United Nations system, and intergovernmental and non-governmental organizations, including organizations of persons with disabilities. The set of questions should address implementation plans for the Rules in States. The questions should be selective in nature and cover a number of specific rules for in-depth evaluation. In preparing the questions the Special Rapporteur should consult with the panel of experts and the Secretariat.
6. The Special Rapporteur shall seek to establish a direct dialogue not only with States but also with local non-governmental organizations, seeking their views and comments on any information intended to be included in the reports. The Special Rapporteur shall provide advisory services on the implementation and monitoring of the Rules and assistance in the preparation of replies to the sets of questions.
7. The Department for Policy Coordination and Sustainable Development of the Secretariat, as the United Nations focal point on disability issues, the United Nations Development Programme and other entities and mechanisms within the United Nations system, such as the regional commissions and specialized agencies and inter-agency meetings, shall cooperate with the Special Rapporteur in the implementation and monitoring of the Rules at the national level.
8. The Special Rapporteur, assisted by the Secretariat, shall prepare reports for submission to the Commission for Social Development at its thirty-fourth and thirty-fifth sessions. In preparing such reports, the Rapporteur should consult with the panel of experts.
9. States should encourage national coordinating committees or similar bodies to participate in implementation and monitoring. As the focal points on disability matters at the national level, they should be encouraged to establish procedures to coordinate the monitoring of the Rules. Organizations of persons with disabilities should be encouraged to be actively involved in the monitoring of the process at all levels.
10. Should extra-budgetary resources be identified, one or more positions of interregional adviser on the Rules should be created to provide direct services to States, including:
 - (a) The organization of national and regional training seminars on the content of the Rules;
 - (b) The development of guidelines to assist in strategies for implementation of the Rules;

(c) Dissemination of information about best practices concerning implementation of the Rules.

11. At its thirty-fourth session, the Commission for Social Development should establish an open-ended working group to examine the Special Rapporteur's report and make recommendations on how to improve the application of the Rules. In examining the Special Rapporteur's report, the Commission, through its open-ended working group, shall consult international organizations of persons with disabilities and specialized agencies, in accordance with rules 71 and 76 of the rules of procedure of the functional commissions of the Economic and Social Council.

12. At its session following the end of the Special Rapporteur's mandate, the Commission should examine the possibility of either renewing that mandate, appointing a new Special Rapporteur or considering another monitoring mechanism, and should make appropriate recommendations to the Economic and Social Council.

13. States should be encouraged to contribute to the United Nations Voluntary Fund on Disability in order to further the implementation of the Rules.

ANNEX 2

AGENDA 22

LOCAL AUTHORITIES

DISABILITY POLICY PLANNING INSTRUCTIONS FOR LOCAL AUTHORITIES

REVISED VERSION

The Swedish Aphasia Association, The National Association for the Prevention of Asthma and Allergies, The Swedish Association of Breast Cancer Societies, The Swedish National Association for Deaf, Hearing Impaired and Language Impaired Children, Swedish Federation of Disabled Persons, Swedish Hemophilia Society, The Swedish Association for the Electrosensitive, The Swedish Association for Persons with Difficulties in Reading and Writing/Dyslexia, The Association of the Swedish Deaf-Blind, The Swedish National Society for Persons with Mental Handicap, The Swedish Association for Rehabilitation of Head Injured Persons (BrainPower), The Heart and Lung Patients Association, The Swedish Heart-Children's Association, The Swedish Association of Hard of Hearing, The Swedish Ostomy Association, The Swedish Association of Neurologically Disabled, The Swedish Psoriasis Association, The Swedish National Association for Disabled Children and Young People, The Swedish Rheumatism Association, The National Society Autism in Sweden, The Swedish Cystic Fibrosis Association, National Association for Hematological Diseases, The Federal Organisation for People Living with HIV, The Swedish Association of People with Stomach and Bowel Diseases, The Swedish Association of Kidney Patients, The Swedish Association for Social and Mental Health, The Swedish Association for Persons Disabled by Accidents or by Polio, The Coeliac Society of Sweden, The Swedish Diabetic Association, The Swedish Epilepsy Association, The Swedish Association of Laryngectomees, The National Association of Stammerers, The Swedish Stroke Association, The Swedish Parkinson's Disease Association, The Swedish Association of Rare Disorders

AGENDA 22

Is to implement the UN Standard Rules by drawing up disability policy plans.

THE STATE, THE COUNTY COUNCIL, the municipality, the enterprise, the organisation etc.

shall

- establish co-operation with the organisations of persons with disabilities as equivalent partners,
- together with the organisations of persons with disabilities, review its own activities to see how they live up to the Standard Rules,
- together with the organisations of persons with disabilities, compile an inventory of the needs of persons with disabilities,
- bridge the gap between present-day resources and the needs of persons with disabilities in a separate disability policy plan,
- write in the plan how the disability aspects are to be included in all future decision-making,
- write in the plan how the co-operation with the organisations of persons with disabilities is to proceed in future,
- evaluate and revise the disability policy plan at regular intervals.

The organisations of persons with disabilities shall

- be given the necessary preconditions to be able to live up to its role of experts on its own issues,
- monitor the fulfilment, evaluation and revision of the plan.

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AGENDA 22

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- Mainstreaming
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Proposed structure of disability policy plan

HUMAN RIGHTS ARE THE BASIS

Decisions by local authorities impact the everyday lives of persons with disabilities. The decisions may concern things like housing, education or care. This being so, it is important that the authorities should include disability aspects in all their decision-making.

The United Nations have unanimously adopted the "Standard Rules on the equalisation of opportunities for persons with disabilities". The Standard Rules are an excellent implement for structuring disability policy. The Swedish organisations of persons with disabilities have devised a method, known as Agenda 22, concerned with drawing up disability policy plans based on the Standard Rules.

The basic ideas are few in number, viz: human rights are the basis of this work, and it is through co-operation between the organisations of persons with disabilities and the local authorities that the best results can be achieved.

This material is entitled "Agenda 22 – Local Authorities -Disability policy planning instructions". It deals with ways in which an authority can draw up a disability policy plan together with the organisations of persons with disabilities. The material includes suggestions concerning the work from idea to plan. Agenda 22 consists of three main parts:

- Characteristics of a good disability policy plan
 - Equal partners
 - From idea to disability policy plan
- At the end of the material there is a set of questions concerning the UN Standard Rules. These questions can be used when the local authority and the organisations of persons with disabilities come to inventory compliance with the Standard Rules.

Swedish local authorities have adopted this method and disability policy plans are being drawn up nation-wide. We now hope that other countries also will be able to benefit from this method, and so we have modified the material so that it also can be used outside Sweden.

The location of decision-making powers on these everyday matters can differ from one country to another. It is to the decision-makers concerned that this publication is addressed.

Stockholm
October 2001

Equality of opportunity – a human right

Persons with disabilities sometimes need more support from the community to achieve the same living conditions as other citizens. That support must never be regarded as a privilege, it is a human right.

For persons with disabilities everyday life can be full of obstacles large and small which prevent people from running their own lives. But things do not have to be this way. There are solutions which could eliminate many unnecessary obstacles. The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities were introduced in 1993 for the purpose of ensuring that persons with disabilities have the same rights as other citizens.

In order to ensure these rights, deliberate, systematic planning is needed. Local authorities are often responsible for a host of fields affecting people's everyday life. They have therefore a special responsibility. A disability policy plan is therefore needed which in order to implement the Standard Rules. The organisations of persons with disabilities are necessary partners in the process of drawing up disability policy plans.

Use the knowledge

Close co-operation with the organisations of persons with disabilities, is essential in order for local authorities in order to be able to plan rationally and cost-effectively.

It is only persons with disabilities themselves who know what living with a disability is like. This being so, it is a waste of resources for society not to use all the knowledge present in the organisations of persons with disabilities. Failure to use that knowledge means that progress towards an equal society will probably be slower than it needs to be. The local authority incurs additional work and expense – what it had intended to will not work in practice and therefore has to be planned all over again.

Standard Rule 18 describes how the role of the organisation of persons with disabilities can be "to identify needs and priorities and to participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities". This means that the organisations are to be accepted as experts on their own issues and must always be consulted on matters concerning them. This makes it important to find good procedures whereby local authorities and the organisations together can draw up good disability policy plans.

On the basis of the UN Standard Rules

The UN Standard Rules are 22 in number and consist of standpoints concerning the responsibilities of States, disability policy guidelines and proposals for concrete action.

The Standard Rules are based on the principle that all citizens are of equal dignity and therefore have the same rights. It is the concern of the society to ensure that resources are fairly distributed.

The Standard Rules are also based on what is termed the environment-related concept of handicap. That means, a handicap can occur in the encounter between persons with disabilities and their surroundings. The causes may be deficiencies of the physical environment or a gap between the service which society offers and the actual needs of persons with disabilities.

Thus it is not the individual who must be adapted and re-modelled in order to fit in with society, it is society which has to be planned so that all citizens have the same opportunities.

The 22 Rules are divided into three groups: Preconditions, Target Areas and Implementation Measures.

Preconditions

The first group of rules, dealing with prerequisites of participation on equal terms, consists of four rules. It begins with the importance of **Awareness raising**, Rule 1, everywhere in society about the needs, rights and potentialities of persons with disabilities. There must also be good **Medical care**, Rule 2, and good **Rehabilitation**, Rule 3, implemented at the right time. Society must be able to offer **Support services**, Rule 4, and technical aids appropriate to the needs of each individual.

Target Areas

The second group of Rules describes the responsibilities of society in eight important target areas. First comes the question of **Accessibility**, Rule 5. If society is to be equal, it must also be accessible to everyone. This applies to the physical environment and also to the availability of information and communication between people.

All children and young persons must, according to their aptitudes, receive equivalent **Education**, Rule 6. Persons with disabilities must also be able to obtain **Employment**, Rule 7, on the same conditions as everyone else. Society must take upon itself to ensure that persons with disabilities have sufficient **Income maintenance and social security**, Rule 8, even if the nature of their disability limits or excludes opportunities of paid work. Everyone has the same rights to **Family life and personal integrity**, Rule 9, persons with disabilities must not be

discriminated against in matters of sexual relations, marriage or parenthood. Persons with disabilities must also be able to avail themselves of **Culture**, Rule 10, amenities both as recipients and in an active capacity. The same goes for **Recreation and sports**, Rule 11, both in-and outdoors activities. Churches and religious assemblies should be accessible so that persons with disabilities will be able to practise their **Religion**, Rule 12, freely.

Implementation

The last group consists of ten overarching rules. Through **Information and research**, Rule 13, society is to augment knowledge concerning the needs of persons with disabilities and in this way is to lay the foundations of consistent **Policy-making and planning**, Rule 14, with disability aspects included in every context. **Legislation**, Rule 15, shall give persons with disabilities a legal basis of participation and equality and **Economic policies**, Rule 16, shall be framed in such a way that disability questions are included as a natural part of ordinary budgeting work. **Co-ordination of work**, Rule 17, shall ensure that the resources of the societies are efficiently used.

The importance of society utilising the knowledge possessed by **Organisations of persons with disabilities**, Rule 18, is a principal theme of the Standard Rules. Rule 18 defines the role which the organisations can play as advisers in the planning, implementation and evaluation of measures concerning the lives of persons with disabilities. In addition, all personnel categories concerned must be continuously provided with **Personnel training**, Rule 19, of such a kind that gives them a knowledge of the needs, rights and potentialities of persons with disabilities. **Monitoring and evaluation of programs**, Rule 20, must be made continuously so the intentions of the Standard Rules can be gradually achieved.

Through **Technical and economic co-operation**, Rule 21, the members of the United Nations can help to improve living conditions for persons with disabilities in the developing countries and support the task of forming organisations of persons with disabilities. Disability aspects must also be a natural component of all **International co-operation**, Rule 22.

Applications of the Standard Rules

The Standard Rules are not legally binding, they are a political and moral commitment agreed on by the members of the international community.

The word "States" at the beginning of each Standard Rule must not be taken to imply that the Rules only apply to the governmental, nation-wide level of society. The Standard Rules can be used as guidelines for disability policy measures at all levels of society, from national to local, but also in private enterprise, organisations and so on.

PART 1. CHARACTERISTICS OF A GOOD DISABILITY POLICY PLAN

If the local authority is to be capable of offering the same opportunities to all citizens, a disability policy plan is needed which will systematically endeavour to make society accessible and participatory. A good disability policy plan has to be based on the following fundamental principles:

• The Standard Rules as guidelines

The plan must be based on the intentions and substance of the Standard Rules.

The 22 Rules can be used as a structure when preparing and drawing up a disability policy plan. Local authorities must go through rule by rule and analyse

- **how** society fulfils the standard rules today,
- **what** has to be done to fulfil the rules,
- **how** it is to be done -objectives and measures.

• Close co-operation with the organisations of persons with disabilities

The organisations of persons with disabilities should be actively involved in the entire process when a plan is to be drawn up or revised, from planning to implementation and evaluation.

In a good plan all needs have to be included. Therefore the plan must be based on a proper inventory of the needs of persons with disabilities, made in close co-operation with the organisations.

• Mainstreaming

The ultimate objective of disability policy planning by the local authority must be for disability policy measures to be integrated in such a way that these aspects can permeate all activities.

Accordingly, they must always be factored in from the commencement of all planning – a principle internationally known as “mainstreaming”.

One logical consequence is that policy measures must as far as possible be financed by what we in Sweden call the principle of responsibility and financing, which means that each activity carries its own costs. People hard of hearing need amplifiers in order to be able to use telephones. The extra expense that this entails must be added to the price, not just of telephones with amplifiers but of all telephones, if the principle is to be complied with.

One of the first steps towards mainstreaming is for the finished disability policy plan to be adopted by the supreme policy-making body or assembly of the local authority. The plan must cover every activity within the authority’s competence.

• Women, children and immigrants

The situation for women, children and immigrants must get special attention in the plan.

There is a risk that women with disabilities suffer dual discrimination, both as persons with disabilities and as women. This makes it important that a gender perspective is included in the disability policy plan. Dual discrimination is also a reality for immigrants.

Children too are often disregarded. Good habilitation, for example, is essential in order for children with disabilities to be able to live on the same terms as other children.

• General and individual measures

Individual measures must always be available to supplement general ones when necessary.

For example, many questions of accessibility can be dealt with through general measures. If public transports also are adapted to suit people with disabilities, more people, will be able to travel by bus or underground. But there will always be persons who need personally designed service.

• Freedom of choice

It is a matter of democratic importance that persons with disabilities should have the same opportunities as everyone else of making their own choices.

Local authorities must be able to offer a service which gives every citizen the opportunity of participation and individual choice.

• Society as an example

Society must set a good example of forward-looking disability policy planning and of communicating the importance of compliance with the Standard Rules in all activities.

If local authorities provide financial support, for example, for teaching, sports, societies, cultural events and so

on, they can put pressure by making demands on the recipients of the grants.

Sometimes public authorities put activities out to contract. In the procurement of such services, it must be stipulated that the contractor has the knowledge necessary to eliminate the risk of persons with disabilities being discriminated. The local authority can also set a good example by employing persons with disabilities.

- **Future co-operation with the organisations of persons with disabilities**

The disability policy plan must describe how the local authority shall cooperate with the organisations of persons with disabilities in the future

The plan must state what consultative groups that are needed and how they are to work rationally. Representatives of the organisations of persons with disabilities are to play an advisory role, as envisaged in Standard Rule 18. The authority will have to consider whether this entails a training responsibility and whether the representatives are to be paid attendance allowances.

- **Objectives**

The local authority's disability policy plan must have long-term objectives laying down that persons with disabilities are to have the same rights as other citizens.

These objectives can very well be defined with reference to the opening sentence of each of the Standard Rules.

- **Concrete measures**

The objectives are achieved through concrete measures which have to be clearly stated the plan.

It must be written down **what** is to be done, **when** each measure is to be completed, **which agency** is responsible for implementation and **how** the measure is to be **financed**. This is very important for the consistent achievement of the objective and also because the plan has to be evaluated.

- **Evaluation and revision**

Procedures of evaluation and revision must be described in the disability policy plan.

The plan must be evaluated annually by a working group with representatives of organisations of persons with disabilities and the local authority. Alternatively, the authority can appoint a special "auditor" to evaluate compliance with its disability policy plan. The plan also needs to be revised at regular intervals.

PART 2. EQUAL PARTNERS

The Agenda 22 approach is based on two inventories:

- What service does the local authority offer to its citizens?
- What support do persons with disabilities need from the community?

The plan must bridge any gap between the two inventories.

Equal conditions

The organisations of persons with disabilities shall be equal partners and be included in the entire process when the plan is made.

The organisations must be involved from the planning until the policy-making bodies adopt the plan. As a logical consequence of the authority endorsing the UN Standard Rules, this endorsement – in keeping with Rule 18 – must logically be reflected by the way the work of drawing up a disability policy plan is organised.

Time and money

To enable the representatives of the organisations of persons with disabilities to do their job properly, it is a good thing if they can be remunerated.

A good disability policy plan must be systematic and well-constructed enough to withstand the political and economic fluctuations. To be able to do this properly the representatives need to spend a lot of time and could therefore need to be paid for their contribution.

Agenda 22 group

The work with a disability policy plan can be organised by an Agenda 22 group.

This group can plan and direct the work, compile analyses and proposals and prepare the final draft version of a disability policy plan. The working group must comprise equal numbers of representatives of the authority and the organisations of persons with disabilities.

Working groups

Working groups can be appointed to compile inventories of municipal activities.

They can also propose measures to be taken. The working groups should be recruited on the same lines as the Agenda 22 group, so as to achieve an equal, representative balance between local authority and the organisations of the disabled.

The organisations of persons with disabilities

The organisations of persons with disabilities can collect and compile data concerning the community support needed by persons with disabilities.

PART 3. FROM IDEA TO DISABILITY POLICY PLAN

The finished plan must relate to the full range of local authority activities.

This being so, the task of compiling a plan should be located directly under the supreme policy-making body or assembly appointing the Agenda 22 Group. Work on the plan can be organised in the following way:

STAGE 1 – inventory of relation to the Standard The supreme policy- making agency or assembly of the local authority decides that a disability policy plan is to be drawn up. **activities of local authorities in Rules**

This work needs to be based on an open-ended inventory of reality,

Working groups make inventories of activities

Agenda 22 Group is appointed which plans and directs the work and compiles analyses and proposals.

to show the extent to which the services authority

with disabilities.

The organisations of persons with disabilities make inventories of their needs of public service.

provided by the local match the needs of persons

An inventory of this kind can be prepared. The compliance of its different Rules.

A draft disability policy plan is prepared.

The plan is adopted by the supreme decision-making body or assembly of the local authority.

carried out by the authority investigating activities with each one of the UN Standard

The inventories should be of the organisations of persons

needs of persons with disabilities will enable them to discover both opportunities and shortcomings that others don't notice. The inventories conclude with each activity preparing a written summary and proposing measures to be taken.

conducted together with representatives with disabilities. Their knowledge of the

If the authority wants to adopt a holistic approach, all activities can be inventoried at once. Otherwise the work can be divided up in such a way that certain areas are investigated one year and the others the year after.

Each Standard Rule refers to the responsibilities of States. By exchanging the term "States" for "local authority", the Standard Rules can be used at this level. The best thing of all, of course, is for all rules – from Rule 1 to Rule 22 – to be reviewed for each individual activity. Otherwise the investigation can be conducted in such a way that each activity is inventoried with reference to the rules which are most relevant to it. For example, when a school is to be inventoried, Rule 6, Education, is very important.

Certain rules are overarching and apply to all sectors of society and therefore need to be used by everybody. This is particularly true of :

- Rule 1 Awareness-raising, which deals with the importance of raising awareness of the rights, needs and potential of persons with disabilities,
- Rule 5 Accessibility, about the importance of access to the physical environment and to information and communication,
- Rule 14 Policy making and planning,
- Rule 18 Organisations of persons with disabilities,
- Rule 19 Personnel training.

At the end of this material there is a chapter called "Questions concerning the UN Standard Rules.

These set of questions can be used when the local authority and the organisations of persons with disabilities come to inventory compliance with the Standard Rules.

STAGE 2 – inventory of the public service needs of persons with disabilities

A thorough survey of needs of persons with disabilities is also needed. It can be done by the organisations of persons with disabilities.

The first phase of the inventory of needs can be for each organisation of persons with disabilities to be tasked with identifying the public service needs of the groups which it represents. It is important that the public service needs of all groups should be factored into the disability policy plan.

STAGE 3 – compilations, analyses and priorities

The Agenda 22 Group compiles and analyses the reports, compares them with the descriptions of needs and drafts a disability policy plan.

It is possible that the local authority's view of compliance with the Standard Rules will in some respects differ from that of the users. If so, the viewpoints of the organisations of persons with disabilities must carry a good deal of weight. When the material has been compiled and analysed, it will become clear in which fields there are deficiencies. Presumably so much needs to be put right that work will have to be spread out over a period

of several years. At this stage it has to be decided which measures are to be taken first and which ones will have to wait.

Priorities can be defined with reference to many different aspects.

The first priority should be to determine that disability aspects are always to be included from the very outset when the local authority is planning new activities and environments. This can be supplemented by a stipulation that disability aspects are to be included in alterations to activities or environments, such as renovations and repairs, re-organisation measures, computerisation and the combination of goal documents and action plans. Other priorities may, for example, refer to particular groups, such as children and old persons. Measures can then be made to concentrate for a certain time on areas of importance to those groups. Another possibility may be for priority to be given to certain activities.

Financial constraints need not be an obstacle.

The disability policy plan must be realistically constructed, so as to be genuinely feasible. It is perfectly possible to work systematically for an equal society even in times of scarcity, if policy measures are organised by stages on the basis of what is economically possible. Then again, what is good for persons with disabilities is often good for other people as well. All passengers, for example, benefit from the existence of both spoken and visible information on public transport.

STAGE 4 – disability policy plan, draft version

The objectives can be framed as visions laying down that society shall be equal and that all citizens shall have equal participation.

These visions can be based on the opening sentence of each Standard Rule.

A good disability policy plan shall be distinct and shall have clear objectives which are achieved by stages, through concrete policy measures.

A disability policy plan extends over a given number of years. In it one can describe, year by year, concrete measures to be taken for the achievement of a particular objective. The plan shall indicate **what** measures need to be taken, **when** they are to be taken, **what agency is responsible** for taking them and **how** they are to be **financed**.

If the measures planned are clearly written into the plan, the latter will be easier to evaluate.

A suggested overall structure is given at the end of this material.

STAGE 5 – adoption of the plan by the supreme policy-making body

The disability policy plan is adopted by the Executive Board, so that it can apply to all activities within the local authority.

QUESTIONS CONCERNING THE UN STANDARD RULES

THIS SECTION CONSISTS OF A NUMBER of questions on each Rule. They can be used, together with the Standard Rules themselves, to chart a local authority's compliance with the UN Standard Rules. Each activity can be inventoried according to the rules most relevant to it. Certain Rules are more generalised and apply to all areas of activity, in which case they need to be used for all inventories.

The overarching Rules are as follows:

- **Rule 1** Awareness-raising
- **Rule 5** Accessibility
- **Rule 14** Policy-making and planning
- **Rule 18** Organisations of persons with disabilities
- **Rule 19** Personnel training

RULE 1

Awareness-raising

"States should take action to raise awareness in society about persons with disabilities, their rights, their needs and their potential and their contribution."

QUESTIONS

Rule 1:1

- How is the local authority spreading information about its resources for persons with disabilities?
- Is the information accessible to persons with disabilities of every kind?
- Is the information adequate, in the sense of all persons with disabilities concerned being fully informed of their rights and possibilities?

Rule 1:2

- What is the authority doing to disseminate the knowledge that persons with disabilities are citizens having the same rights and obligations as everyone else?

Rule 1:3

- What is the authority doing to encourage mass media to describe persons with disabilities in positive terms?

Rule 1:6

- How is the authority encouraging enterprises in the private sector to take disability aspects into account in all their activities?

Rule 1:7

- What is the authority doing to raise awareness among persons with disabilities of their rights and possibilities?

Rule 1:9

- Are awareness-raising measures included in the authority's training of various personnel categories?

RULE 2

Medical care

"States should ensure the provision of effective medical care to persons with disabilities".

QUESTIONS

Rule 2:1

- Does the local authority have action programmes aimed at detecting, assessing and treating impairments at an early stage?

Rule 2:2

- What training do caring personnel receive in the detection of impairment and referral to appropriate services?

Rule 2:4

- Do caring personnel have continuous access to relevant methods and technology?

Rule 2:6

- In what way does the authority ensure that persons with disabilities have access to any regular treatment and medicines they need?

RULE 3**Rehabilitation**

“States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning”.

QUESTIONS

Rule 3:1

- Does the local authority have rehabilitation programmes of its own for different groups of persons with disabilities?

Rule 3:2

- What rehabilitation measures exist today for people with different disabilities?

Rule 3:3

- Are the rehabilitation measures equal to needs? If not, what is lacking?

Rule 3:4

- What possibilities do persons with disabilities and their families have of participating in the design and organisation of rehabilitation services concerning themselves?

Rule 3:6

- Are persons with disabilities and families encouraged to involve themselves in the rehabilitation of others, e.g. as teachers, instructors or counsellors?

Rule 3:7

- Are the organisations of persons with disabilities consulted when rehabilitation measures and programmes are being formulated or evaluated?

RULE 4**Support services**

“States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights”.

QUESTIONS

Rule 4:1

- Is the authority providing the support which persons with disabilities need with regard to
 - assistive devices?
 - personal assistance?
 - interpreter services?

Rule 4:4

- Are services free of charge to the user?

RULE 5**Accessibility**

“States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. For persons with disabilities of any kind, States should

(a) introduce programmes of action to make the physical environment accessible; and

(b) undertake measures to provide access to information and communication. ”

QUESTIONS

Rule 5:1

- Does the local authority have an action programme systematically aimed at making the physical environment
 - both in and out of doors – accessible to everyone, for example in
 - homes?
 - other buildings?
 - public transport and other means of communication?
 - streets?
 - other outdoor environments?

Rule 5:2

- Do persons professionally involved in the design and construction of the physical environment have access to continuous information on disability policy and measures to achieve accessibility?

Rule 5:3

- Are the accessibility requirements of more groups of persons with disabilities affected included in the design and construction of the physical environment from the beginning of the designing process?

Rule 5:4

- Are organisations of persons with disabilities consulted:
 - when standards and norms for accessibility are being developed?
 - when construction projects are being planned?

Rule 5:5

- Is the information provided by the authority on diagnosis, rights and available services and programmes accessible to:
 - all persons with disabilities affected?
 - their families?
 - their representatives?

Rule 5:6

- What strategies are used for making information services and documentation accessible:
 - to persons with visual impairment?
 - to the deaf/blind?
 - to deaf persons and persons with auditory impairment?
 - to the intellectually handicapped?
 - to dyslexics?
- Do the measures taken correspond to actual needs?

Rule 5:7

- How do deaf children and children with auditory impairment get access to sign-language tuition through out their education?
- Does the authority help parents to obtain instruction in sign language?
- Does the authority know how many deaf, deaf/blind and hearing-impaired citizens are in need of interpreter services?
- Are there interpreters for everyone who needs them?

Rule 5:9

- How does the authority monitor the accessibility of television, radio and newspapers
 - to persons with visual impairments?
 - to the deaf/blind?
 - to the deaf and hearing-impaired?
 - to the intellectually handicapped?
 - to dyslexics?

Rule 5:10

- Are accessibility aspects for all groups concerned taken into consideration from the very beginning when new computerised information and service systems are built up?
- If this has not been the case, will existing systems be adapted to make them accessible to persons with disabilities?

Rule 5:11

- Are organisations of persons with disabilities consulted before new information services are developed?

RULE 6

Education

“States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system”.

QUESTIONS

Rule 6:1

- Does the local authority ensure the education of persons with disabilities in integrated settings?
- Does this education form an integral part of educational planning, curriculum development and school organisation?

Rule 6:2

- To make education accessible, is there provision of
 - sign language interpreters?
 - other appropriate support services?
 - routines making education accessible to all?

Rule 6:3

- How are parent groups and organisations of persons with disabilities involved in the education process?

Rule 6:6

- Has the authority formulated a policy for education in mainstream schools?
- Are curricula flexibility, addition and adaptation allowed for?
- Are quality materials, ongoing teacher training and support teachers provided?

Rule 6:8

- Does special education exist for those whose needs cannot be adequately met within the general school system?
- Does the quality of such education equal that of other education?

Rule 6:9

- Are there special schools for deaf/hearing-impaired and deaf/blind persons in need of sign language education?
- If not, how are the needs of these pupils provided for?

RULE 7

Employment

“States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market”.

QUESTIONS

Rule 7:2

- What does the local authority do to encourage the integration of persons with disabilities into open employment?

Rule 7:3

- How many people are employed by the authority? How many of them have a disability?
- Do workplaces under the authority’s aegis have action programmes to make them accessible to persons with disabilities?
- If so, what measures are included in the programme:
 - measures to encourage the use of assistive devices?
 - measures to adapt working hours to individual needs (e.g. through flexible working times, part time, job-sharing)?
 - measures to improve vocational rehabilitation?
 - other measures?
- To what extent have these measures been implemented? Were they adequate?

Rule 7:4

- What is the authority doing to raise public awareness so as to overcome negative attitudes and prejudices concerning workers with disabilities?

Rule 7:5

- What is the authority doing to create favourable conditions for the employment of persons with disabilities in its own activity?

Rule 7:6

- What are conditions like today at workplaces under the authority's aegis, do persons with disabilities have the same prospects as others
 - in connection with hiring?
 - as regards promotion?
 - as regards pay increases?
 - as regards participation in personnel training programmes?

Rule 7:7

- What employment opportunities can the authority offer to persons with disabilities whose needs cannot be met in open employment?

Rule 7:9

- Does the authority co-operate with organisations of persons with disabilities concerning all measures relating to persons with disabilities in working life and in the job market?

RULE 8

Income maintenance and social security

"States are responsible for the provision of social security and income maintenance for persons with disabilities".

QUESTIONS

Rule 8:1

- What income support is provided for persons who, by reason of their disability,
 - have temporarily lost their income?
 - have received a reduction in their income?
 - have been denied employment opportunities?
- Is the support in question sufficient to provide persons with disabilities with an equivalent living standard?
- A disability can entail additional expense. Has this been taken into account in the planning of income support?

Rule 8:3

- What income support is provided for individuals undertaking the care of a person with a disability?

Rule 8:4

- Does the authority have special action programmes aimed at providing incentives for persons with disabilities to seek employment? If so, do the action programmes provide opportunities of
 - vocational guidance?
 - vocational rehabilitation?
 - vocational training?
 - job placement?
 - income support in the meantime?

RULE 9

Family life and personal integrity

"States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood".

QUESTIONS

Rule 9:1

- Does the local authority enable persons with disabilities to live with their families?
- Are respite-care services available?

Rule 9:2

- Does the local authority provide counselling for persons with disabilities who wish to set up a family?

Rule 9:3

- What is the local authority doing to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities?

Rule 9:4

- Can the authority offer persons with disabilities information about taking precautions against sexual and other forms of abuse?

RULE 10

Culture

“States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis”.

QUESTIONS

Rule 10:1

- Are different cultural activities such as dance, music, literature, theatre and so on accessible in such a way that persons with disabilities can engage in artistic activity?
- Are cultural performances and services accessible to persons with disabilities?

Rule 10:2

- Is information concerning cultural performances and services accessible at
 - theatres?
 - museums?
 - cinemas?
 - libraries?

Rule 10:3

- Is modern technology used as a means of making cultural performances and services accessible to all persons with disabilities?

RULE 11

Recreation and sports

“States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports”.

QUESTIONS

Rule 11:1

- Are the activities themselves accessible in such a way that persons with disabilities can engage in sporting activity and avail themselves of leisure activities?
- Are these amenities accessible to spectators with disabilities?

Rule 11:2

- What is the authority doing in order for the local tourist trade to make its activities acceptable?

Rule 11:3

- How is the authority supporting sports activities for persons with disabilities?
- Are persons with disabilities being supported so as to enable them to participate in national and international events?

Rule 11:4

- Do persons with disabilities participating in sports activities have access to instruction and training of the same quality as other participants?

Rule 11:5

- Are organisations of persons with disabilities consulted in the development of services for persons with disabilities?

RULE 12

Religion

“States will encourage measures for equal participation by persons with disabilities in the religious life of their communities.”

QUESTIONS

Rule 12:1

- How is the local authority helping to make religious activities accessible to persons with disabilities?

Rule 12:2

- How is the authority encouraging the distribution of information on disability matters to religious institutions and organisations?

Rule 12:3

- What is the authority doing to make religious literature accessible to persons with sensory impairments?

Rule 12.4

- Are organisations of persons with disabilities consulted in the development of measures for equal participation in religious activities?

RULE 13

Information and research

“States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities”.

QUESTIONS

Rule 13:1

- Has the local authority collected statistics concerning, for example,
 - the education situation for pupils with disabilities?
 - conditions in the workplace for persons with disabilities?
 - employment opportunities for persons with disabilities?
 - additional private expenditure entailed by a disability?
 - the impact of spending cuts and increased charges on the finances of persons with disabilities?

Rule 13:2

- Does the authority have a databank on
 - different groups of persons with disabilities and their several needs?
 - the addresses of all organisations of persons with disabilities?
 - services and programmes of concern to persons with disabilities?

Rule 13:3

- How is the authority supporting research on
 - the impact of social and economic conditions on persons with disabilities and their families?
 - ways in which services and support measures can be developed?

Rule 13:5

- Is the authority encouraging the recruitment of persons with disabilities to work with data collection and research on disability questions?

Rule 13:7

- What measures is the authority taking to disseminate knowledge and information on disability at
 - political levels?
 - administrative levels?

RULE 14

Policy-making and planning

“States will ensure that disability aspects are included in all relevant policy-making and national planning”.

QUESTIONS

Rule 14:1

- Does the local authority have a disability policy plan?
- Is it based on the UN Standard Rules?

- Does the plan contain concrete measures with
 - a time limit for the implementation of each measure?
 - the agency responsible?
 - funding?

Rule 14:2

- Has the disability policy plan been drawn up in close co-operation with organisations of persons with disabilities?
- Are disability aspects included in the authority's development plans from the very outset?

Rule 14:4

- Are there check-lists, for example concerning the accessibility measures which may be needed in different connections?
- If so, are the check-lists being used in such a way as to encourage action?

RULE 15**Legislation**

"States have a responsibility to create the legal bases for measures to achieve objectives of full participation and equality for persons with disabilities".

QUESTIONS

Rule 15:2

- Has the local authority been criticised for not complying with the legislation applicable to persons with disabilities?
- If so, has the authority taken action to ensure that the situation does not recur?

RULE 16**Economic policies**

"States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities".

QUESTIONS

Rule 16:1

- Is the local authority's expenditure on adaptations and other resources affecting persons with disabilities included as part of the regular budget or budgeted separately?

Rule 16:2

- Does the authority give financial support to projects and other developmental measures relevant to persons with disabilities?

Rule 16:4

- Does the authority have a special disability development fund which can support pilot projects and self-help programmes at grassroots level?

RULE 17**Co-ordination of work**

"States are responsible for the establishment and strengthening of national co-ordinating committees, or similar bodies, to serve as a national focal point on disability matters".

QUESTIONS

Rule 17:1

- Is there a permanent co-ordinating committee for disability questions within the local authority?

Rule 17:2

- If so, how is the co-ordinating committee recruited?

Rule 17:3

- How are organisations of persons with disabilities represented on the co-ordinating committee?

Rule 17:4

- What resources does the co-ordinating committee have at its disposal?

RULE 18

Organisations of persons with disabilities

“States should recognise the right of the organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters”.

QUESTIONS

Rule 18:1

- How does the local authority encourage and support
 - the formation of organisations of persons with disabilities?
 - existing organisations of persons with disabilities?
 - co-operation between organisations of persons with disabilities?

Rule 18:2

- How does the authority co-operate with organisations of persons with disabilities today?

Rule 18:3

- What role do organisations of persons with disabilities play in matters of support and service and other measures affecting persons with disabilities? Are they in a position to
 - identify needs and priorities?
 - participate in the planning of measures?
 - participate in the implementation of measures?
 - participate in evaluations?
 - contribute actively towards increasing public awareness?

Rule 18:4

- What is the importance of organisations of persons with disabilities to
 - their members?
 - society?

Rule 18:5

- To what extent are organisations of persons with disabilities represented within the local authority's administration?

RULE 19

Personnel training

“States are responsible for ensuring the adequate training of personnel at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities”.

QUESTIONS

Rule 19:1

- Do personnel categories within the local authority often coming into contact with persons with disabilities receive training in the disability field?
- If so, what does the training comprise?
- What training is received by other personnel in the disability field?

Rule 19:3

- Are persons with disabilities usually involved as teachers, instructors or advisers in staff training programmes relevant to persons with disabilities?
- Are these training programmes developed in consultation with organisations of persons with disabilities?

RULE 20

National monitoring and evaluation of disability programmes in the implementation of the Rules

“States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalisation of opportunities for persons with disabilities”.

QUESTIONS

Rule 20:1

- How are the local authority's disability policy plan and other action programmes for persons with disabilities evaluated?
- What role is played by organisations of persons with disabilities when disability policy plans and action programmes for persons with disabilities come to be evaluated?
- How and to whom are the results of the evaluations disseminated?

Rule 20:5

- Are the procedures as to how and when a disability policy plan and an action programme are to be evaluated written into the document itself?

RULE 21

Technical and economic co-operation

"States, both industrialised and developing, have the responsibility to co-operate in and take measures for the improvement of the living conditions of persons with disabilities in developing countries".

QUESTIONS

Rule 21:1

- What resources does the local authority have for refugees and immigrants with disabilities?
- Are the special needs which immigrants and refugees with disabilities may have included in disability policy plans and action programmes for persons with disabilities?

Rule 21:2

- When the authority co-operates or has exchanges with developing countries, are disability questions included as part of this process?

Rule 21:3

- Are organisations of persons with disabilities consulted when the authority is planning projects relevant to persons with disabilities in developing countries?

Rule 21:4

- In projects concerned with technical and economic co-operation with the developing countries, does the authority give support to
 - the development of the skills, abilities and potentials of persons with disabilities?
 - employment-generating activities?
 - dissemination of appropriate disability-related technologies and know-how?

Rule 21:5

- Is the authority supporting the formation and strengthening of organisations of persons with disabilities in other countries
 - by supporting initiatives taken by organisations of persons with disabilities?
 - by other means?

Rule 21:6

- When the authority engages in co-operation or other exchanges with developing countries, are measures taken to improve the knowledge of disability issues possessed by the staff involved?

RULE 22

International co-operation

"States will participate actively in international co-operation concerning policies for the equalisation of opportunities for persons with disabilities".

QUESTIONS

Rule 22:2

- When the local authority co-operates internationally, are disability aspects included in
 - negotiations?
 - information exchange?
 - development programmes?

Rule 22:3

- How does the authority support the international exchange of knowledge and experience between
 - non-governmental organisations concerned with disability issues?
 - research institutions and individual researchers involved in disability issues?
 - representatives of field programmes and of professional groups in the disability field?
 - organisations of persons with disabilities?
 - national co-ordination committees?

PROPOSED STRUCTURE OF DISABILITY POLICY PLAN

Long-term overarching objectives

- such as “In our municipality all citizens should be able to participate in cultural life on equal terms”.

Summary of the inventories

- how the municipality’s different activities work in relation to the Standard Rules.

Summary of the social service needs of persons with disabilities

- general description of the total municipal service needs of persons with disabilities.

Long-term timetable

- indicating the fields in which measures need to be taken and how those measures are to be spread out over a specified year.

Objectives and concrete measures

- description of targets and measures for each field to be addressed within the period covered by the plan. The measures shall be concretised in such a way as to indicate the steps to be taken, when they are to be completed, what agency is responsible for their implementation and how they are to be funded.

EXAMPLE:

Municipal information shall be made accessible by

- adapting the entrance and telephone switchboard of the local government offices
 - installing a lift and text-telephone (implementation time, agency responsible, funding).
- All information from the local government office shall, when so requested, be available on cassette or in an easy-reader version (implementation time, agency responsible, funding).
 - the premises where municipal council meetings are held shall be made accessible (implementation time, agency responsible, funding). Future co-operation with organisations of persons with disabilities.
 - forms of future co-operation with local organisations of persons with disabilities.

Evaluation and revision

- procedures as to when and how the plan is to be evaluated and revised.

