

BEYOND DE-INSTITUTIONALISATION:

The Unsteady Transition towards an
Enabling System
in South East Europe

2004

DISCLAIMER

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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

EXECUTIVE SUMMARY



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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.

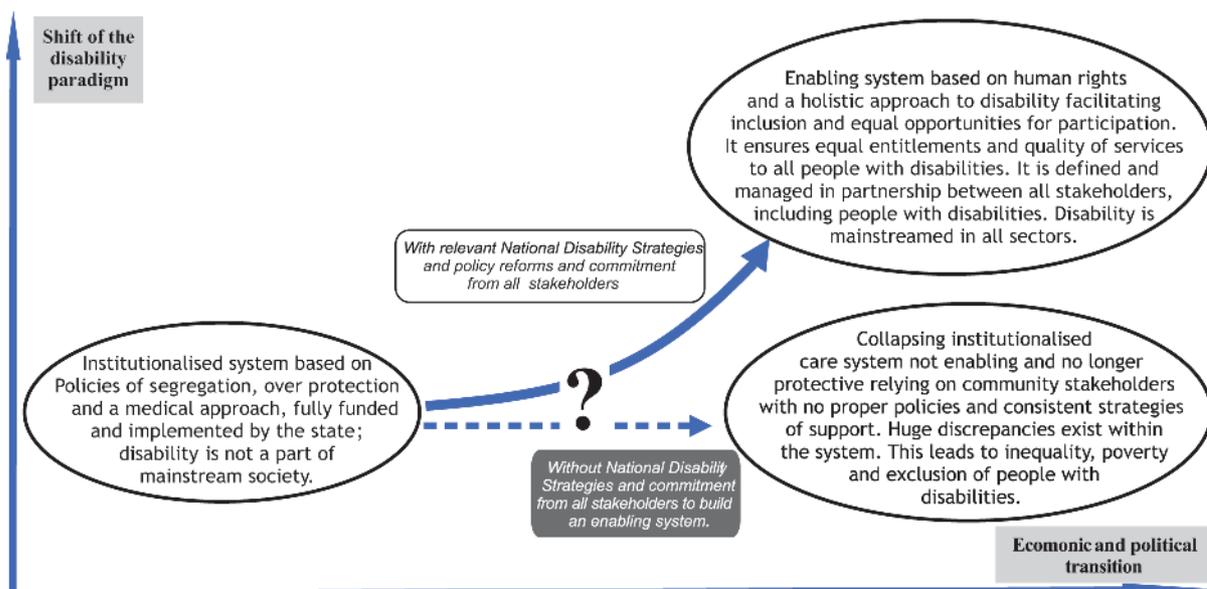
THE DISABILITY MONITOR INITIATIVE: EQUAL OPPORTUNITIES AND FULL PARTICIPATION AS A GOAL

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, implementing 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*