



The NGO role in advocacy for the human rights of people with disabilities in Bulgaria

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Summary

The treatment of people with disabilities in Bulgaria fails to meet relevant international standards on equal access to opportunities and the right to an integrated life. There is a need for a radical change in societal attitudes with respect to people with disabilities, to enable them to become a driving force for social processes and contribute actively to the building of an open civil society. NGOs have a vital role to play in this process, and this paper highlights the main advocacy goals they have developed to promote the rights of people with disabilities.

This paper describes three projects targeting people with disabilities, which illustrate the different focuses of NGO advocacy in Bulgaria. The first one contributes to the improvement of the educational level of people with disabilities and helps them to find jobs. The second facilitates the vocational training of disabled pedagogues, whose work will include showing that people with disabilities can solve the problems of other people with disabilities. The third project empowers people with disabilities by creating a communication platform and providing possibilities for adapted information access.

Background

People with disabilities in Bulgaria continue to face a number of important challenges.¹ The financial problems associated with Bulgaria’s transition to a market economy have served as an excuse for not treating people with disabilities in a decent way², yet many of the changes needed to improve their human rights situation would require only minimal public resources. The real reasons for not taking action can instead be attributed in large part to attitudes and bad practices that are deeply rooted in society. There is no awareness on the part of the general population of the difficulties faced by people with disabilities, many of whom are prisoners in their own flats. Policies and attitudes dating from the Communist regime — which separated people with mental and physical disabilities (including very young children) from the rest of society — have persisted. Legislation intended to provide an accessible environment for people with disabilities has so far proved ineffective.³ People with disabilities remain invisible and effectively excluded from full participation in the political, social, economic and cultural life of their communities.

It is still very rare to find a person with disabilities in a decision-making position in Bulgaria. People with disabilities have inadequate educational opportunities and suffer from high levels of unemployment. Due to architectural barriers and reluctance on the part of teachers and public administration, children with disabilities cannot take advantage of the Bulgarian educational system and almost no efforts are made to integrate them into the mainstream school system. There is a widespread prejudice that workers with disabilities are less productive and require special care and assistance, thereby constituting a burden for the employer. If employed, people with disabilities are generally unskilled, low-paid workers. But many can only find jobs in segregated, sheltered workplaces that do not contribute to their social integration. To date, little effort has been made to identify and develop the real capabilities of people with disabilities to work on the open market, rather than in sheltered workshops.⁴

Advocacy Priorities for NGOs

Over recent years, the Government has taken a number of steps towards tackling the many barriers to integration faced by people with disabilities in Bulgaria. For example, the National Strategy for Integration of People with Disabilities was adopted in 2002.⁵ It also recently announced a new legal initiative⁶ aimed at ensuring an accessible urban environment for people with disabilities. At the municipal level, every large municipality or city now has a 'coordinator for disabilities', whose task is to develop and help implement an overall plan to improve the situation of people with disabilities.⁷

However, the NGO sector in Bulgaria also has a vital role to play in this process⁸ and NGOs have been active in the process of implementing the National Strategy. A number of general advocacy goals can be illustrated in their general approach to the development of projects targeting people with disabilities.

- *Promoting the social model of disability: overcoming barriers of exclusion*

In the past, actions in favour of people with disabilities were usually based on the 'medical' (or individual) model of disability, according to which people with disabilities are viewed as 'sick' and in need of being 'cured' or cared for by medical professionals.⁹ Impairment and chronic illness exist, and they sometimes pose real difficulties for people with disabilities. This does not make them less suitable to participate in society, but most people have not been brought up to accept them as they are.

Fear, ignorance and prejudice all contribute to the development of barriers and discriminatory practices, including, for example, an 'inferiority complex' and sense of isolation on the part of people with disabilities, and exclusionary attitudes on the part of the general public. However, thanks to the advocacy of NGOs, and also to the new governmental initiatives, these barriers are starting to be addressed.

The medical model is gradually being replaced by the new 'social model', which is premised on active participation, equal opportunities, and the integration of people with disabilities into mainstream life. At its simplest, the Social Model¹⁰ shifts the focus from people's impairments, to removing the barriers that people with disabilities face in their everyday life and acknowledging society's failure to take diverse needs into account. It aims to move policy away from a medical, charity and care agenda, towards a rights-based, equality agenda.

Clearly, the 'social model of disability' has important implications for education systems, particularly with reference to primary and secondary schools. Prejudicial attitudes toward people with disabilities are not inherited, but learned through contact with the prejudice and ignorance of others. Therefore, to challenge discrimination against people with disabilities, it is important to begin in schools. In Bulgaria, the fight for the inclusion of all children, however severely disabled, into one mainstream education system, will not make sense unless the differences between the 'social' and the 'medical' model of disability is understood.

- *Addressing the environmental and psychological barriers that people with disabilities face*

In its broadest sense, the social model of disability is about a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment - whether physical, sensory or intellectual. The barriers encountered by people with disabilities include inaccessible education systems and working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluation of people with disabilities through negative images in the media.

Serious efforts have been made by NGOs in Bulgaria to mobilise people with disabilities to join local community-based organisations for self-help and self-advocacy purposes. Organisations of people with disabilities have become more open to the public, and placed more emphasis on working to raise public awareness and gaining support for independent living practices. This facilitates the participation of disabled people in the decision-making process, as well as the design of more feasible and sustainable development projects. NGO advocacy initiatives now include providing training and professional orientation for people with disabilities, and strengthening the capacity of their own NGOs.

The social model of disability does not ignore questions and concerns relating to the impairment itself or the importance of medical and therapeutic treatments. It acknowledges that, in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of medical and other services. NGOs therefore also work to accumulate funds for the equipment of special treatment centres and day-care centres for people with disabilities.

Nonetheless, the real tragedy is that Bulgarian society continues to discriminate and exclude people viewed and labelled as disabled, and this is the subject matter of emancipatory disability research. NGO efforts are often aimed at establishing social contacts among people with disabilities, both at work and in their free time, and thus contributing to the extension of their social and support network.

- *Promoting cooperation between NGOs and local government*

In recent years, there has been a positive trend in improved cooperation between civil society organisations and local governments, when it comes to improving the living conditions and integration of people with disabilities. Now the advocacy initiatives of most NGOs include regular meetings between people with disabilities and decision-makers.

One of the earliest contributions of NGOs in Bulgaria was to set up arenas where people and government could communicate. NGOs mediated between central government and local communities in several conflicts. From the conflicts of the mid-1990s, there emerged the realisation that the government can not handle everything: it doesn't have the expertise, the professionalism, the good will or the experience, nor the sensitivity and the openness needed to facilitate the representation of all national agendas, communities and groups. People with disabilities became aware that they are best represented not through individual effort, or periodic mass protest, but through civic groups and NGOs that are continuously engaged in dialogue with government at the various levels.

Government authorities realised that they could benefit from the situation in several ways. The structured dialogue with civil society organisations means that the government knows what is going on, and that citizens become involved in decision-making, which means they are less likely to protest or complain. At the same time, the government realised that the NGOs have expertise that could improve the performance of government structures (and ultimately, help win elections).

Along with the municipalities, NGOs became central initiators of various forms of policy-making and strategy development on the situation of people with disabilities. NGOs such as the Centre for Independent Living pursue the agendas of vulnerable groups, and train such groups in the skills of self-advocacy and negotiation. Initially, municipalities (mayors in particular) welcomed NGOs on an *ad-hoc* basis, partly because of their expertise, but also because they realised that NGOs had influence over the sections of the public most likely to be discontented and critical. Later, municipalities also began partnering with NGOs on *projects*, because the NGOs knew how to develop projects that would attract outside donors and municipalities did not, and these projects thus brought in fresh resources. Eventually, such cooperation has evolved into fully-fledged policy and development partnerships.

Examples of successful projects

The following three projects were developed and implemented by local NGOs in Bulgaria, and aim to improve the education, training and employment opportunities of people with disabilities. The first project contributes to the educational level of people with disabilities, and helps them to find jobs and increase their self-esteem. The second project facilitates the vocational training of disabled pedagogues (resource tutors), whose work will include showing that the problems of people with disabilities can be solved by persons with disabilities. The third project empowers people with disabilities by creating a communication platform and providing possibilities for adapted information access.

- *Project 1: Creation of a sustainable network of rehabilitation/consultation centres for people with disabilities (RCCPDs):*

A partnership of two Bulgarian NGOs carried out this PHARE-funded project: the *Union of Disabled People in Bulgaria* and the *Club "Sustainable Development of Civil Society"*. It aimed to create a sustainable network of RCCPDs throughout the country, to provide training, business information and consultation for people with disabilities and the organisations representing them.¹¹ The RCCPDs have now become reliable partners in solving all kinds of problems related to social isolation, unemployment and job opportunities for people with disabilities. Specifically, the project achieved the following objectives:

- promoting private initiative and entrepreneurship among people with disabilities and improving their business qualifications;
 - improving the expertise of local NGOs representing people with disabilities, in the areas of project development and management and establishing effective partnerships;
 - creating a platform for training local business consultants and the representatives of regional associations of people with disabilities, to enable them to provide people with disabilities with business consultation;
 - mediating between disabled entrepreneurs and credit institutions for small businesses; and
 - informing people with disabilities about local authorities' decisions, and in turn providing analysis to the local municipality councils about the main obstacles to the employment of people with disabilities.
- *Project 2: Virtual Incubator for Prequalification into Resource Tutors for People with Disabilities*

This is a 24-month project in the field of vocational training, funded by the European Commission's 'Leonardo da Vinci' Programme. The Bulgarian partners are the Department of Psychology and Pedagogy of the University of Plovdiv and the Regional Development Agency.¹² The project aims to improve the employment opportunities and self-confidence of unemployed or disabled pedagogues, by providing them with an opportunity to continue their vocational training. The project created a new curriculum for resource tutors for people with disabilities (older than 18 years) who have not had the chance to get access to education and training. Following their training, the resource tutors will, in turn, make vocational training accessible for people with disabilities, or help them continue their education. Thus, the project will answer the identified need for a specially tailored, flexible and more effective approach to the education and training of people with disabilities.

- *Project 3: "Information portal for people with disabilities"*

The Bulgarian Information Portal for People with Disabilities, a first of its kind, was launched in March 2004. Only open source software was used to create the portal, which was designed with a simple interface and navigation, for people who are blind and use Braille display or a speech synthesis. A discussion forum provides a place to meet other people in a similar situation, or to give and offer advice, and visitors have the opportunity to publish news and articles. There is a

directory of contact information for Bulgarian government and state institutions; information about NGOs and social legislation concerning people with disabilities or accessible infrastructure; and an overview of forthcoming events and an "Entertainment" section.

The Information Portal for People with Disabilities is an initiative of the Consulting Centre "Public Mediator" (CCPM), which was financially supported by RSICT Agency. The site is developed and hosted with the help of the Internet Rights Bulgaria Foundation (IRBF), as a part of their *NGO Bulgaria* project. The portal is a zone aiming to provoke and establish informal discussions on topics related to the situation of people with disabilities in Bulgaria, and provide a virtual meeting place for cooperation and contacts.¹³

¹ Detailed statistics on the situation of people with disabilities in Bulgaria are not available for analysis or public policy decisions. For example, precise statistics are not available on the precise number of people with disabilities, the type and severity of their disabilities, and their living conditions — including their housing conditions, employment status and level of education. The only real data available, with some degree of proximity, was collected with regard to persons in institutions. The results of the 2001 census show that more than 5 per cent of the population has some level of disabilities (265,353 people according to the Official Bulletin 2001 issued by the National Statistical Institute, NSI). In 2005, funded by the EU Statistical Directorate, the NSI did conduct research on the current situation for people with disabilities, according to which the number of people with disabilities was 263,143 (of these, 92 per cent were aged 16-64, and 72 per cent were reliant on disability benefits).

² People with disabilities receive a range of financial assistance, including free public transportation, reduced prices on modified automobiles, and free equipment such as wheel chairs. However, as in other areas, budgetary constraints mean that such payments have fallen behind.

³ Legal provisions were introduced governing the construction of accessibility features in new buildings and urban areas (Regulation no. 6 of 26 November 2003), but there is no realistic penalty or workable mechanism to assure that the environment created will be barrier-free for people with disabilities. As a result, even though access features add only a small percentage (if any at all) to the cost of the new building, new constructions continue to take place ignoring the need for accessibility. Almost all major buildings, including schools, universities, libraries, government buildings, courts and theatres, remain inaccessible in Bulgaria, as does the entire transport system.

⁴ Moreover, today sheltered workplaces in Bulgaria no longer enjoy their former special advantages. The sheltered workplaces have been commercialised and put on an equal market footing with other businesses. They still have some tax exceptions, but in reality most of their working employees are non-disabled people — workers with disabilities are only 'on the books' in order for the businesses to meet their formal requirements.

⁵ *Strategy for Integration and Equal Possibilities of Disabled People, as part of the National Development Program 2001-2005 of the Bulgarian Government*, published in 2002 by the Council of Ministers (State Gazette).

⁶ Regulation no. 6 of 26 November 2003

⁷ This includes housing, transportation, and the task to monitor all municipal program and activities, such as employment, trade, transportation projects, art and culture, in order to insure that such activities make provision for persons with disabilities.

⁸ In Bulgaria, there are several national associations organised around specific disability groups (i.e. physically disabled, deaf people, blind people). These were created before 1989, and have continued to operate as umbrella organisations, funded by the State. After 50 years of communist regime it is understandable that Bulgaria still lacks experience in building grassroots organisations' capacity, demanding accountability for social problems from the business community, enforcement of legislation by civic actions, and advocacy with the governments. However, despite all those factors, many local organisations have also been set up over the last ten years.

⁹ In the medical model, the emphasis is on dependence, backed up by the stereotypes of disability that evoke pity, fear and patronising attitudes. Usually the focus is on the impairment, rather than the needs of the person. The power to change is viewed as being in the hands of the medical and associated professionals, with their talk of cures, normalisation and science.

¹⁰ The 'Social Model' of disability can be dated back to 1975, when a newly formed British group of people with disabilities, the Union of Physically Impaired Against Segregation, published a short book, *Fundamental Principles of Disability*. Shortly after that, a disabled lecturer, Mike Oliver, tried to introduce the concepts contained in this book to a group of social work students. The Social Model has since become internationally recognised as the driving force behind the disability agenda and a cornerstone of the disabled people's movement. Today, the disabled people's movement believes the 'cure' to the problem of disability lies in the restructuring of society. Unlike medically based 'cures', which focus on individuals and their impairment, this

is an achievable goal and to the benefit of everyone. This approach, termed the 'social model of disability', suggests that disabled people's individual and collective disadvantage is due to a complex form of institutional discrimination as fundamental to our society as sexism, racism or heterosexism.

The social model of disability can also be used to understand the family lives and personal relationships of disabled people. It emphasises the role of the cultural environment in the socialisation of disabled people. The society in which we all grow up usually sees impairment as unattractive and unwanted. This instils dilemmas and conflicts in the parents of disabled children, who are dependent upon what they have learned about disability from the world around them, as they figure out their feelings and how to treat their children. People who become disabled later in life also have to cope with this cultural backdrop that they were themselves socialised in. It is therefore not surprising that parents are often at a loss about how to bring up a child born with disabilities, and both people with and without disabilities often do not know how to respond. This helps to explain why, for some people, coming to terms with a disabled lifestyle represents a personal or family tragedy.

¹¹ The project's main activities include: selection of trainees; preparation and implementation of training on entrepreneurship, management of NGO projects, and support to the establishment of regional RCCPDs, aiming at setting up a sustainable network.

¹² The other participating countries are Greece, Portugal and the UK.

¹³ The URL of the site is <http://www.123.ngo-bg.org>