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## **DISABILITY AND AUTONOMY: THE CASE OF BULGARIA**

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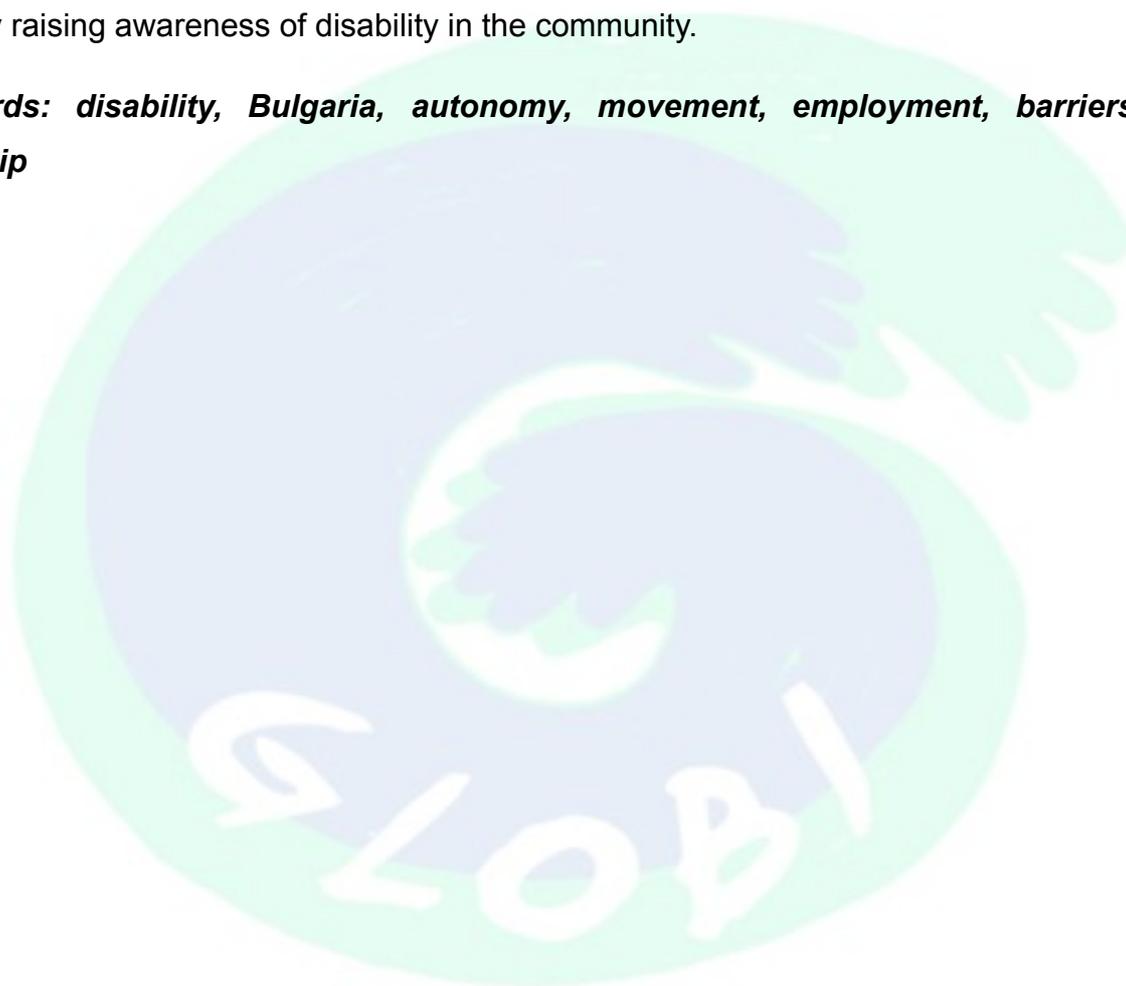
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## **ABSTRACT**

The article explores notions of disability worldwide and identifies those shaping the disability discourse and policies in Bulgaria. It reflects on how these policies relate to two of the major aspects of personal autonomy – autonomy of movement and access to employment. In spite of major legislative changes in recent years, Bulgarian people with disabilities still face considerable barriers to social participation. Independent living is hampered by factors such as inaccessible architectural environment and transport services, inadequate system of disability assessment and assistance provision, and high rates of unemployment. Further steps for introducing changes in these areas should be accompanied by more rigorous monitoring and accountability standards, as well as by raising awareness of disability in the community.

***Key words: disability, Bulgaria, autonomy, movement, employment, barriers, active citizenship***



## **INTRODUCTION**

People with disabilities are often faced with physical, attitudinal, information and communication barriers, difficulties accessing social and healthcare services and employment, as well as inadequate policies (WHO, 2012, UNICEF & IDA, 2013). In the European Union, their numbers amount to about 10-15% of the population (MfLSP, 2012a). According to the Union of Persons with Disabilities, in Bulgaria, the majority of them are excluded from life in the community (UPDB, 2009). Full participation in society is related to the concept of active citizenship, which is realized along the three dimensions of social security, personal autonomy and political influence (DISCIT, 2013). The aspect of personal autonomy will be discussed in relation to two of its major constituents – autonomy of movement and access to employment. Autonomy of movement is a necessary prerequisite for the exercise of all other rights and freedoms, while access to employment secures not only financial independence but also a medium of social interaction; therefore both are regarded as having uttermost importance in the disability discourse.

## **NOTIONS OF DISABILITY IN SOCIETY**

### **The Medical Model of Disability**

The predominant model of disability in the 19<sup>th</sup> century was determined by the fast development of medical science and industrialization, which led to a medicalization of impairment and institutionalization of people with disabilities in segregated residential and educational settings (Galis, 2011). This so-called *medical approach* viewed people with disabilities as having impaired functionality and dependency (Oliver, 1996, cited in Gutman et al., 2012). It postulated that disability is caused by health conditions and its limitations lie within the individual, i.e. the individual is deficient in one or more aspects of his/her functioning. The emphasis was on prevention, treatment, remediation (Linton, 1998 quoted in Gutman, 2012:203). Disabled individuals were expected to adjust to their social, cultural, or educational environment as much as they could, without relying on any significant changes initiated by and involving the environment itself. As Carson (2009:9) points out, this model had a negative impact on the people with disabilities' own perception of themselves leading them into believing that having a disability automatically excludes them from social activities. Such an 'internalised oppression' (ibid) challenged people with disabilities' effort to take steps for ensuring an independent and autonomous life.

### **The Social Model of Disability**

In the mid-20<sup>th</sup> c., as a result of the social justice struggle of individuals with disabilities (Gutman, 2012), disability was re-defined and the focus shifted from the individual psycho-physical deficit to

the socio-material surroundings. The origins of disability were found in 'physical/structural barriers and intellectual barriers in labour, urban design and institutions, together with biased cultural perceptions of difference and dissimilarity' (Galis, 2011:828). For the social model of disability, the disabling factor was not the individual difference but the uninviting and inflexible social and material world structures, designed to suit the needs of the non-disabled. The solution was seen in the legal and judicial protection of civil rights, consultations, peer counseling, independent life, removal of barriers, deinstitutionalization, social integration and inclusion (Ivkov, 2006 cited in Ivkov, 2007:18).

## **The Relational Perspective**

Although the significance of the social model of disability is undeniable, it has been argued that it disregards the individual perception of impairment, the various manifestations of impairment, as well as the interaction of the individual with the environment (Galis, 2011:828). Some disability activists, like Shakespeare (2013a), point out that impairment does affect people, sometimes independently of social barriers. Shakespeare affirms that 'it is the interaction between the intrinsic impairment and environment that creates either the problem or the solution' (2013b, 4:43). A 'workable compromise' (WHO, 2011:4) between the medical and the social model is sought for in the International Classification of Functioning, Disability and Health (WHO, 2001), which adopts the 'bio-psycho-social- model'. Although the 'ICF is [not] only about people with disabilities; in fact, it is about *all* people (WHO, 2001:7), its contribution is in the development of a relational understanding of what determines disability (Imrie, 2004). The latter is thought to occur at three levels – bodily impairment, limitation in activity and restriction of participation, which are influenced by personal and environmental factors (WHO, 2012:3). All these factors need to be taken account of when approaching disablement and securing the well-being and active social participation of people with disabilities.

## **The Human Rights Approach, the Capability Approach, Active Citizenship and Autonomy**

In the second half of the 20<sup>th</sup> century, the growing human rights movement gave rise to an approach that came to see people with disabilities as persons and right holders, whose differences might be or might be not socially and economically accommodated (Quinn & Degener, 2002, cited in Rioux and Carbert, 2003:2). The human rights approach posited that differences associated with disability are 'inherent to the human condition' and do not hamper the possible contributions to society but only diversify their range, as well as that of the mechanisms for people with disabilities to fulfill their rights (Rioux and Carbert, 2003:2). One of the ways to realize and safeguard these rights is through encouraging and securing people with disabilities' active citizenship (Zepke,

2013). Active citizenship can be defined as 'full and effective membership of society', 'living a decent life in accordance with the prevailing standards in society, being able to act autonomously, being able to participate in social and political life... and having "civic" orientations to the political community and to one's fellow citizens' (Andersen & Halvorsen, 2002:12-13, cited in DISCIT, 2013). This understanding of active citizenship highlights three major interrelated and complementary aspects – social security, personal autonomy and political influence (DISCIT, 2013). While these goals are shared by individuals with and without disabilities, people with disabilities are particularly disadvantaged in achieving them.

An insightful means of achieving these goals towards establishing a personal state of well-being is offered by the capability approach. It was developed out of the principles of Amartya Sen's theory of economic growth (Sen, 1999, cited in Graham et al., 2011:137). According to Sen, as individuals have different abilities, an equal distribution of goods will fail to address inequality, unless their capabilities of making use of these goods, of 'converting opportunities into outcomes' (ibid), are developed. Instead of focusing on the availability of resources (or goods), the capability approach focuses on the individual ability to use these resources. As far as disability is concerned, it stresses the need to support the development of individuals' capabilities that would enable them to achieve a wide range of 'functionings', i.e. 'the various things a person may value doing or being' (ibid). Graham et al. (2011) warn that this approach may mislead into locating capabilities only within the person, in this way promoting the individual deficit model. Therefore, they stress the need to draw on the social model of disability and its conceptualization of 'access'. The capability approach has also been recommended as a complementary theory to the human right approach (Barbuto et al., 2013), which shows its powerful potential and interactivity with other models and approaches to disability.

On a more practical level, Graham et al. (2011) use Burbules, Lord and Sherman (1982)'s illustration of the different nature of the two aspects of access – criterion and condition. The criterion of access can be represented by the height of a child trying to reach a shelf, while the height of the shelf will be the condition of access. A focus on catering only for the criterion aspect leads to a medical model thinking. Improving the conditions of access is necessary as well to empower persons with disabilities to live a life they have a reason to value. As far as the autonomy of persons with disabilities is concerned, the conditions of access is determined by numerous factors, out of which we will look at those impeding or strengthening the autonomy of movement and access to employment in Bulgaria.

# THE CASE OF BULGARIA

## The Notion of Disability

Influences of the medical model in Bulgaria can still be found in legal documents' definitions of disability. According to the additional provisions to the new Act on the Integration of Persons with Disabilities (AIPD, 2005, art. 1.1), disability is 'any loss or impairment in the anatomical structure, physiology or mental health of an individual'. The definition is based on the functional-deficit paradigm, without any recognition of the complex biosocial medium in which a person lives and acts (Ivkov, 2007:15). AIPD's definition of 'a disabled person with permanent disability' is even more problematic as it focuses on a reduced working capacity, an assessment carried out by a medical expert body, and makes quite a disturbing functional comparison to the 'healthy' person. In the same vein, the Health Act (2004, art. 101.3) links the assessment for a child's 'ability for social adaptation' to a healthy individual's capacities. Such comparisons suggest a variation from the assumed standard norm, i.e. abnormality. Ivkov (2007:4) interprets these definitions as discriminatory and as a 'triumphant march' of medical definitions 'in spite of the various declarations and loyalty to the social model of disability'.

It is difficult to erase traces of the medical model after a long history of depriving people with disabilities of a place in society, and viewing their state in negative terms both by religious and secular power. A reminiscence of this attitude became the object of extensive media attention in 2008, when the abbot of the well-known Troyan Monastery drove a person in a wheelchair out of the monastery premises, stating that he and the group of Finnish persons with disabilities who were visiting the monastery had no place there (Dermenzhieva, 2010). The communist regime, too, denied the right of persons with disabilities to formal citizenship. The totalitarian state attempted to put a veil over everything that would reveal its weaknesses (Zarichinova, 2013). Persons with disabilities were treated as stumbling blocks to the goal of building up a healthy society, an extra burden that authorities did not have the willingness to deal with. This stand not only gave rise to a policy of neglect, but also injected an attitude of indifference in society itself.

After the political changes following the 1989 overthrow of the regime and culminating in Bulgaria's joining the EU in 2007, a gradual change started due to the country's new international policy obligations. Bulgaria had already ratified the European Convention for the Protection of Human Rights and Fundamental Freedoms in 1992, additionally ratified the European Social Charter in 2000, and is presently following the guidelines of the European Disability Strategy 2010-2020 (MfLSP, 2012a:5). The United Nation's Convention on the Rights of Persons with Disabilities (UN, 2006) was signed in 2008 and ratified in 2012, while the ratification of the accompanying Protocol is still pending (UN, 2014). The issues concerning people with disabilities are addressed in over 46

acts and regulation documents (UPDB, 2009:14). The Anti-Discrimination Act (ADA) (2004, art. 4.1.) guarantees protection against any kind of discrimination, including that based on disability. In 2012, the National Action Plan for Equal Opportunities for Persons with Disabilities (MfLSP, 2012a) was updated, and an Action Plan Containing Measures to Bring the Legal Framework and Policies in Bulgaria in Accordance with the UNCRPD was devised (CM, 2012). On the whole, changes in legislation and government action plans in the past few years, especially in the direction of deinstitutionalization and removal of architectural barriers, show a political will to comply with international standards and requirements. Nevertheless, the Ministry for Labour and Social Policy acknowledges the fact that further measures need to be taken to facilitate the transition from the medical model of disability to one based on social and human rights (MfLSP, 2012a).

## **Autonomy of Movement**

The securing of a barrier-free environment in Bulgaria is one of the most serious obstacles for people with disabilities in Bulgaria (MfLSP, 2012:8), although it has been legally settled in a number of documents, such as the Anti-Discrimination Act (ADA, art. 5), the Urban Developmental Plan (2001, cited in ANED, 2012), the Act for the Integration of Persons with Disabilities (AIPD, 2005, art. 33). However, the updated Strategy for the Provision of Equal Opportunities for Persons with Disabilities 2008-2015 (MfLSP, 2012a:7) recognizes the fact that 'the greater part of [persons with disabilities] continue to be isolated and unable to go out of their homes'. That compromises fundamentally their fair chance of leading an autonomous life and being socially active.

A substantial part of the public buildings in the larger cities have been adapted for access by people with disabilities, however that is not the case in smaller towns and villages. Even in the capital of Sofia, the 2011 monitoring report on the accessibility of public schools, conducted by the Centre for Independent Living revealed that only 5 out of 176 schools are totally accessible (ANED, 2012:4). In the period of 2007-2012 most of the 268 cases brought to the Anti-Discrimination Commission on the grounds of disability were related to inaccessibility (ANED, 2012:5). On a positive note, that demonstrates the availability of a mechanism for people with disabilities to claim their rights before the state structures of justice.

Freedom of movement is also dependent on access to transport services, the responsibility for the creating of which lies with the Ministry for Transport (AIPD, 2005, art. 34.1. & 34.2). However, the inaccessibility of the newly-built Sofia metro exposed the insufficient applicability and control of legislative norms. In 2011, the Anti-Discrimination Commission ruled that the metro's construction presented architecturally hostile environment and caused direct discrimination against persons with disabilities (BHC, 2012a). Also, ANED finds that although bus stations might be accessible for wheelchair users, that might not be the case with the vehicles themselves (2012:3). Only a

number of public buses and trams and specialized buses with a tail lift are in service (MfLSP, 2012:9). Specialized accessible rail road carriages are available only on three major routes (ANED, 2012:3). Furthermore, inaccessible streets and sidewalks are particularly dangerous for visually impaired people (BHC, 2014:55). Only 10% of the traffic lights have been equipped with audible signal devices, which has caused fatal incidents with blind people (ibid).

All in all, inaccessible environment still presents a major barrier for disabled people's autonomous living. The disability activist and wheel-chair user, Petar Kichashki, highlights the consequences of inaccessibility: 'The free movement of people and capital is one of the main pillars of democracy, but where is this freedom when the bank, the insurance company, the state or the municipal institution is inaccessible?' (Dermenzhieva, 2010). One of the problems slowing down the process could be the lack of monitoring and control. ANED (2012:5) notes that no account of audit reports are present in the Report on the Implementation of the Action Plan for Equal Opportunities for Persons with Disabilities for 2011, and concludes that the issue of disability has not been dealt with in all its complexity.

The autonomy of movement for people with severe disabilities is conditioned also by the availability of personal assistance. In Bulgaria, the assessment for obtaining the service is based on a point system quite lacking in reason and fair chance. Panayotova (2014), who is the president of the Centre for Independent Life and a wheel-chair user herself explains, 'If you cannot get up from your bed, the maximum is 3 points. If you go to work, you are given 50 points. That is absurd because in order to go to work, you need to go out of bed, but in order to do that, you need an assistant.' Kichashki calls this 'an awfully unprofitable and honestly erroneous policy' (Dermenzhieva, 2010). It basically means that persons with affirmed work incapacity of 100% turn out to be excluded from the chance to receive a personal assistant, as they are granted less qualifying points than persons with a lower percentage of disability who have already been included in a social activity. As a result of this flaw in the social system, many persons with a disability do not qualify to receive the help of personal assistant and are at risk of exclusion from any type of social life.

## **Access to Employment**

Having access to paid work is a powerful means of increasing personal autonomy. The Labour Code (LC) (art. 8.3) and the Employment Promotion Act (EPA) (2002, art. 4) forbid any discrimination against people with physical or intellectual disabilities. The Anti-Discrimination Act (art. 16) obliges employers to adjust the working place according to the needs of the disabled person as soon as s/he is employed unless the expenses for that are 'unjustifiably high'. The LC (art. 315) binds employers with more than 50-member staff to assign annually working positions

for people with a reduced working capacity amounting to 4-10% of the total number of staff. The EPA (art. 36.2) entitles companies who have employed a person with a permanent disability to receiving financial incentives for up to a year. Besides finding a job at the free market, people with disabilities can be engaged in the workforce as employees at the so-called specialized co-operations or as self-employed. The Agency for Persons with Disabilities provides grants for starting and expanding people with disabilities' business enterprises (MfLSP, 2012b). Grants are also available to employers for introducing adaptations of the work place and opening up vacancies for persons with disabilities (MfLSP, 2014). However, the number of beneficiaries is markedly low due to the limited budget allocated for these projects (e.g. only 12 employers received grants on the former criteria, and 32 applicants on the latter criteria in 2013 (MfLSP, 2014:7).

The legal measures do not manage to effectively alleviate the access for people with disabilities to employment. According to the National Statistical Institute (NSI, 2014b), 245,600 people were outside the workforce because of poor health or disability in 2013. The number seems significantly lower than the one provided for 2011 for people with poor health or disability aged 15-64: 58,900 unemployed and 450,800 outside the workforce (NSI, 2014a). Yet, at the beginning of 2013, the Centre for Independent Living presented data that while the percentage of employed people with disabilities in Europe is 45%, in Bulgaria it is 33% (CIL, 2013). Also, there is a highly disproportionate ratio between the number of employed non-disabled people (71%) and the employed disabled people (33%) (ibid).

Access to employment is seriously hampered by factors we have already discussed in relation to architectural and transport barriers, and availability of personal assistance. It is also adversely affected by the system of disability assessment, which is based on a medically-informed concept of reduced working capacity. Thus, the system allows for a blind person to be assessed with 100% working incapacity, which seriously undermines his/her chances of employment in cases where the employer is unaware of the complex nature of disability and the increasing variety of possibilities for work engagement available with the advancement of technologies nowadays (ZD, 2014). A survey among employers presented by the vice-president of the Bulgarian Industrial Chamber, D. Brankov (Dnevnik, 2014), reveals that the obstacles for engaging disabled people in the workforce as seen by employers are: the inaccessible architectural environment, the applicants' low level of education and shortage of finances for equipping work places. Though these reasons are quite legitimate, it can be argued that a major factor is still the predominant and ubiquitous lack of acceptance of people with disabilities in society. The Union of Persons with Disabilities (UPDB, 2009:16), too, sees lack of understanding and stigma as the foremost problem

its members are facing. In other words, prejudice acts as a barrier upon which other barriers are constructed.

## **CONCLUSION**

Bulgaria is still in a transition from the medical model to a social and human rights-based model, the process being differently paced in different areas. The exercise of active citizenship is still a major challenge for persons with disabilities in the country, as it is only possible after a 'definitive abandoning of the medical model', both in policies and practices, has occurred (Barbuto et al., 2013:73). The paper showed that although the demonstration of political will to provide people with disabilities with an equal chance for social participation and autonomy is existent, the level to which legislative norms have been put into practice is not of a considerable consequence. Independent living is still seriously hampered by multifarious factors, out of which we looked at inaccessible environment, inadequate social policy in terms of personal assistance, and high rates of unemployment. Particular attention should be paid on securing the monitoring, control and legal responsibility for violating the established norms. The process of architectural barrier-removal needs to encompass a larger part of the country's territory. Major changes need to be introduced in the transport system, which is largely inaccessible, and thus turns many of the measures for removing architectural barriers ineffectual. The social system of disability assessment and assistance provision needs to be reevaluated and modernized, too. The criteria for acquiring a personal assistant should be optimized and expanded. The state should direct more subsidies into encouraging the business sector to open up towards people with disabilities assuming both roles of employees and entrepreneurs. An indispensable role in these multi-directional processes will be played by an increased general public understanding and accepting of disability. This should be achieved through regular and systematic campaigns for raising awareness and forming positive attitudes towards persons with disabilities. In the designing of all these changes and their implementation, the participation of people with disabilities themselves is indispensable. Full autonomy cannot be achieved without the fulfillment of the other two components of active citizenship – security and influence (DSCIT, 2013). An integrated approach, strong vision and mutually supporting policies and practices are needed to reinforce the active participation of all Bulgarian citizens in society.

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