

About people living with disabilities

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More than a billion people are estimated to live with some form of disability. According to the *World Health Survey* around 785 million (15.6%) persons 15 years or older live with a disability, the *Global Burden of Disease* estimates a figure of around 975 million (19.4%) persons. Of these, the *World Health Survey* estimates that 110 million people (2.2%) have very significant difficulties in functioning, while the *Global Burden of Disease* estimates that 190 million (3.8%) have "severe disability" (WHO World Report 2011). The number of people with disabilities is annually growing. There is a higher risk of disability in older age-groups as societies are aging at a rapid pace. There is also a global increase in chronic health conditions, such as diabetes, cardiovascular diseases, and mental disorders, which all significantly influence the nature and prevalence of any resulting disability. Patterns of disability in a particular country are influenced by trends in health conditions, environmental and other factors. Additionally, experiencing disability is greatly influenced by the interaction of health conditions, personal factors, and environmental factors. While society views disability as a disadvantage, not all people with disabilities are equally disadvantaged. The prevalence of disabilities is disproportionately high in so-called high risk groups or vulnerable populations. There is a higher occurrence of disabilities in lower-income than in higher-income countries, similarly, in the lowest strata of society, among women, and the elderly. Furthermore, people with low income levels, the unemployed, or those with basic educational qualifications are at an increased risk of disability.

The social position of people living with disabilities after the turn of the millennium: Trends in Hungary

The condition of people living disabilities, meaning educational opportunities, presence on the labour market, social acceptance, and political activity, has changed substantially following the turn of the millennium. This can be attributed in part to the appearance and adoption of European currents in Hungary, but also to the wider and more pronounced social integration of the disabled, as well as to

Hungarian and international legal regulations and diverse policy initiatives in this area. The latter entails initiatives in education, the labour market, civil society; additionally, the role of individuals, groups, as well as state/public initiatives aiming for the realization of disability rights and goals should not be discounted either.

Currently more than a billion people are estimated to live with some form of disability, or about 15% of the world's population (based on 2010 global population estimates). This figure seems higher than the previous World Health Organization estimates, dating from the 1970s and 1980s, which suggested a figure of around 10%. (WHO Report). Mere numbers do not reveal the whole picture of the condition of people living with disabilities; nevertheless it is clear that the affected population is continuously increasing in number, especially among the elderly, thereby requiring intervention to better their living conditions and environment, including integration into the educational system and the labour market.

In Hungary until the last decade of the 20th century due to specific historical reasons the question of people living with disabilities did not become a public issue; rather it remained a family affair to be dealt with (Horváthné, 2009). The dawn of the 21st century without doubt brought meaningful positive changes; thus the living environment and conditions of the disabled have been transformed, the notion of integration came to the forefront, and the process of inclusion gained pace.

The progressive disability policies of the new millennium approach the condition and situation of people living with disabilities not primarily as a health, rehabilitation or social policy issue, but rather elevate it to the level of human rights. The mere declaration of fundamental rights and the fight against manifestations and practices of negative discrimination is insufficient and it must be supplanted by positive action and even positive discrimination to remedy the adverse effects of exclusion and to mitigate the disadvantages facing the disabled (KSH, 2003).

An overview of the terminology of disabilities

The definition of disabilities varies quite substantially depending on the particular area or symposium under consideration. The diverse definitions of the European Union member states are compiled by the *German Federal Ministry of Health (Bundesministerium für Gesundheit und Soziale Sicherung)*. Even from this compendium it is clear that national definitions and applications of models to be used for the identification of disabilities are far from being uniform. In Denmark no single definition is used. People with disabilities are

normally identified as all those who require support, care or specialized treatment to regain or develop their skills. This includes physical, mental, social, and invisible disabilities.

In Finland the disabled are designated as individuals who due to a disability or medical condition are unable to fulfil their normal daily activities on a long-term basis (Law on the Disabled, 1987). According to the social welfare services an individual is considered disabled when his ability to work and potential to earn income is substantially compromised.

In Spain an individual is considered disabled if he has congenital or acquired physical, sensory or mental conditions, which negatively affect his ability to receive education, to work without any limitations or to fully function in society. (EC, 2004)

Disabilities form a central aspect of special education. In this case the word comes from medical terminology referring to long-term or irreversible limitations in physical body functioning and attendant personality disorders. It is seen as a deviation from the average "normal" in a negative sense. It is an organic dysfunction of the central nervous system, any of the sense organs, speech impairment or dysfunction of the limbs or gross motor ability, which persists throughout the entire lifespan and is irreversible (Spaller, 2006). In Gordosné Szabó Anna's definition, which approaches the special education aspect of disabilities, it is an umbrella term that denotes impairment, activity limitations and participation restrictions (Horváthné, 2008). It refers to an individual with a chronic health condition and is characterized by contextual factors.

Psychology approaches the question of disabilities focusing on its mental aspect; those individuals are identified as disabled who suffer from mental, sensory or motor function impairments or limitations. Children who are unable to study in a regular school setting, attend special classes or are enrolled in entirely specialized schools. (*Encyclopaedia of Psychology*, Almássy, 2007).

The pedagogical approach searches for a definition in the fields of educational theory and pedagogy. Here this condition is traced to its medical origins; it is a condition that persists due to genetic causes or some form of impairment. However, from a pedagogical point of view the main focus is on mental, visual, hearing impairments, physical limitations of the limbs, and speech impediment; additionally, disorders of emotional life are also emphasized as they can lead to alterations in the personalities and personality development of the affected individuals (Báthory & Falus, 1997).

In sociology, as Giddens (2008) stated, disability has an individual and social model as well. In the individual model the main source of problems in the lives of disabled individuals stems from their personal limitations: physical impairment leads to a certain degree of disability or functional limitation. Contrary to this, in the social model the

causes for disability lie not in the individual but rather in society. Here disabilities manifest due to barriers placed in front of those living with disabilities, thus preventing their full participation in society.

In their professional/academic discourse the various actors' use of phraseology tends to reflect the focus of their activities concerning disabilities. *In health care the term patient, in education the student with special needs, and in employment the term employee with disability as sanctioned by the Labour Code is used* (Horváthné, 2009).

In 2001 the *International Classification of Functioning, Disability and Health (ICF)* was introduced. The *ICF* is a classification of health-related domains of individuals relative to their specific living conditions and environmental factors. Its primary approach is not medical, rather focuses on bridging any limitations and dysfunctions.

"A variety of conceptual models has been proposed to understand and explain disability and functioning. These may be expressed in a dialectic of "medical model" versus "social model". The medical model views disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behaviour change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy. The social model of disability, on the other hand, sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life." (ICF, 2003)

The disabled in Europe, similar to the United States, make up one of the most numerous minorities and following the elderly are the largest beneficiaries of public services. Data budget outlays directly connected to disability expenditures are the third significant segment in the social public services budgets of EU member states, behind old age pensions and medical expenses, but by far exceeding costs connected with unemployment (Maschke, 2011).

Besides this the European Commission in a summary report on social integration emphasized that in most member states people living with disabilities are faced with potential exclusion, which is tangibly signified by the continuously elevated risk of impoverishment faced by the chronically ill and the disabled. Thus the issue of disabilities has become a European and member state level social affair in the past years in which even the affected individuals have

become active participants and actors. The significance of the disability issue is further shown by that 97% of EU citizens think that more should be done for the integration of people living with disabilities.

Organizations and support networks in favour of the disabled

In the social integration of the disabled great emphasis is placed on the various support groups and organizations. Currently in Hungary on behalf of the disabled three different types of organizational forms are in existence. These may be state/public, non-profit and for profit organizations with the dominance of the first two. From the perspective of the state primarily the legally mandated responsibilities must be fulfilled and the European and Hungarian norms in disability services must be maintained. In the case of non-profit organizations a wider scope of activities is discernible depending on which segment of the disabled they care for and what level of social responsibility they take and in that specific area how pronounced is state/public involvement.

As a good example of state involvement in this field is the work of *Parliamentary Committee on Youth, Family, Social Affairs, and Housing*. The Committee's area of responsibility encompasses the supervision of the social policymaking activity of the powerful *Ministry of Human Resources* and all its subordinate organizations dealing with family and social affairs and the youth.

The wide ranging activities of this committee are signified by the establishment in June 2010 of seven subcommittees, on controlling, pensions and senior citizen affairs, youth, population demographics, housing, the disabled, and on the government policies of the eight years preceding the current government. Most of these subcommittees have by now ended their mandate. (Parliament website, 2012) As indicated one of the subcommittees deals with disability affairs and as such it forms an active part in the political discourse of the country in this area, however, similar to the *Committee on Human Rights, Minorities, and Religious Matters* it is only partially active in networking with NGOs involved in this field. In the political arena such cooperation is only visible at the national level while it is greatly diminished on the regional and local scale.

In the case of municipal governments at the local or regional level the typical public organizations do not in particular form functioning cooperating entities, rather, in line with the available options present to them attempt to create functioning systems with NGOs and for profit organizations.

Besides the state/public organizations an important role is played by NGOs which on one hand function as advocacy bodies for their specialized areas and on the other, though they lack their own support networks, aim to elevate life quality of the disabled and strengthen their social integration. One of the most prominent representatives of such NGOs in Hungary is the *Equal Opportunities of Persons with Disabilities non-profit Ltd.*, which operates under the principle of "nothing about us without us". The goal of the organization is that through its specialized programs the issue of disabilities should reach a widening segment of the general society. In its realization, besides the Hungarians, numerous foreign organization/groups are also actively involved. One of these is the *EUFAMI*, founded in 1992 in Belgium as a democratic international non-profit organization with the stated goal of improving care and welfare for people affected by mental illness. Another important organization is the *Disabled Peoples International*, which has a sizable worldwide presence encompassing more than 130 countries.

We can count as disabled advocacy NGOs those national associations which take over public responsibilities in favour of specific groups of disabled.

Currently in 2012 we can mention nine such organizations. Although they represent diverse groups of people living with disabilities, however, especially when cooperating they can successfully represent the interests of the disabled (support schemes, benefits, disabled friendly employment conditions). *The National Federation of Disabled Persons' Associations* is in existence since 1981. Its mission is to map and articulate the particular interests of the disabled, harmonize them with other groups but at the same time initiate amendments or new laws to improve the opportunities and living conditions of disabled persons; furthermore, to provide support and assistance in the formulation of strategies for the creation of lacking educational, cultural, sport, employment, and leisure opportunities (MEOSZ, 2012).

The *Hungarian Federation of the Blind and Partially Sighted* is one of the oldest advocacy organizations in the country. It was founded in 1901, although not at the initiative of the blind. Its mission, similarly to goals advanced in favour of the disabled, is the protection, advocacy of the interests of the blind and partially sighted.

The *Hungarian Association of the Deaf and Hard of Hearing* and its precursor organization have been in existence since 1802 using the current name since 1952. The Association provides various services to its members including fully accessible information with its own newspaper, employment opportunities; supports initiatives for independent living, offers subsidized recreational and transportation opportunities, as well as cultural, sport and leisure programs. Additionally, sign language services, legal assistance, and

psychological counselling are also available; lastly it organizes various conferences dealing with the deaf and hard of hearing (SINOSZ, 2011).

Besides the three largest organizations other advocacy groups also have prime significance. Their list includes the *Hungarian Association for Persons with Intellectual Disability*, the *National Autism Association*, the *Hungarian Association of Transplant Recipients*, the *National Association of the Deafblind*, the *Soteria Foundation* for people living with emotional problems, and *National Association of Employers of the Disabled*.

The principle of integration only partially functions among the various organizations; if we consider state subsidies then there is a certain measure of linking coming from above while the desire to act effectively for the common cause and the attendant professionalism and experience of the involved organizations creates horizontal linkages.

From the already listed network of organizations another needs to be mentioned, the *National Federation of Disabled Persons' Associations*, established in 2001, representing roughly 600 thousand disabled people. The express goal of the Association is to enhance cooperation among all disabled advocacy organizations with the exception of the *Soteria Foundation* and the *National Association of Employers of the Disabled*. However, the question that still persists is whether is it possible to consider these organizations, functioning as they do, as genuine NGOs, or rather as state/public entities fulfilling a public function although formally operating as NGOs.

Summary

In this brief paper I aimed to give an overview of the current state of disability affairs in Hungary with a focus on what it means at the present to be living with disabilities in society, how does it translate to numbers, what are the definitions of the terms used, and what type of organizational structures are available to help those disabled in need.

The functioning and work of the involved groups and organizations is difficult to quantify and is often diffused. Certainly the data provided by the *Hungarian Central Statistical Office* is greatly beneficial; however, mere figures do not offer even a glimpse of the actual inner workings of these groups. In Hungary among these groups we can find only a single form of integration which is the advocacy function they practice. When considering the specific groups of disabled, it is indeed this function that has prime significance. The organizations function independently, each with its own specific focus

and target area; nevertheless, oftentimes they are obliged to cooperate for the realization of their common goals and principles.

In the lives of people living with disabilities these organizations fulfil essential functions; supporting them effectively should not be relegated to the state alone but should also entail the involvement of private companies and other actors in the economy. Beyond such cooperation, i.e. financing, we must take into consideration the express knowledge that has been accumulated in these groups, therefore the work of the *National Federation of Disabled Persons' Associations*, as an umbrella organization, should be further encouraged.

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