

Policy Paper

HCLU on Disability Rights

There are over 37 million persons with disabilities living in Europe who experience severe discrimination and segregation. In the last two decades a movement has been started by and for people with disabilities. This movement has demanded, amongst other things, equal rights, inclusion into society and participation in its life, and a re-definition of disability.

The Hungarian Civil Liberties Union [HCLU] contends that these aims are worthy of support and that the Hungarian state must overcome its past policy of ignorance, prejudice and inaccessibility. Instead, the Hungarian state must continue the process begun by Act XXVI of 1998 “to ensure equality of opportunity, independent living and active participation in the life of society for persons living with disability”. In light of this, some questions arise: What is a disability? For example, if I have HIV/AIDS, do I count as disabled? What are my rights as a disabled person? Are there any international standards on disability rights? What are ways to ensure or promote disability rights? Does Europe have a unified standard and strategy? What is the history of the disability movement? Where does Hungary stand in relation to international standards?

What is a Disability?

There are two main approaches to the definition of people with disabilities: the social and the medical. Of the two, the medical approach is the more prevalent. The first *International Classification of Impairments, Disability and Handicap* [ICIDH] published in 1980 by the World Health Organization [WHO] based its definition of disability on

the medical approach. It identified disability as the impairment of some physical or mental capacity that others command to a standard degree. Such a definition locates the phenomenon of disability exclusively within the individual.

In contrast, the social approach puts disability in the framework of an environmental situation, it focuses on the way disability is imposed externally on the individual. According to this approach, the impairment of a capacity does not count, in itself, as disability. It becomes a disability if it is treated by society in such a manner as to disadvantage the person with impairment. In other words, physical and mental impairments do not involve social disadvantage directly. They give rise to such disadvantage through the mediation of the attitudes and practices of the disabled person's social environment. Mobility impairment is a fact about an individual; but the denial of the facilities (e.g., ramps) that would allow for people with mobility impairments to access public buildings or commercial units is a fact about the social environment. Hearing impairment is a fact about the individual; but the denial of the access to the media to people with a hearing impairment is a fact about the social environment. Mental impairment is a fact about an individual; but the practice of segregating people in institutions even if they were able to live in community is a fact about the social environment. All sorts of impairments are facts about the individual; but the employment policy that allows them to be significantly underrepresented in the job arena, even if they were able to do many jobs, is a fact about the social environment.

The debate surrounding the definition of disability cannot be dismissed as a matter of mere semantics. In fact, it makes up the principles of equal rights of the disability community. If we subscribe to the notion that disabled people are simply lacking something then it becomes much more difficult to see the responsibility that

the able-bodied community bears for their systematic disadvantages. Complementing the medical approach with the social one helps to reveal this responsibility.

The social approach highlights, for example, the fact that in our societies AIDS constitutes a disability. Since people with HIV or AIDS are usually stigmatized by their social environment, and stigmatization involves systematic disadvantages in employment, housing, access to health care, or data protection, we have to see such people as having a disability. *The Americans with Disabilities Act* 1990 [ADA] (see below) classifies people with HIV or AIDS as disabled under the subsection: “someone who has no impairment but is treated by an employer as if they have a substantially limiting impairment”.

Recently, the WHO has published a new ICDH re-examining the definition of disability. In the new classification, disability is considered as an umbrella term, and combines the medical definition with the social definition. It starts from the fact of impairment, but it also acknowledges the role that environmental factors play in restricting functioning. HCLU maintains that this approach is basically correct. People with disabilities suffer from some impairment. But it is not the impairment in itself that constitutes the fact of disability but the way society treats it. The status of the disabled person is that of a human being treated by the social environment with indifference, prejudice, and discrimination.

What should the state do for its disabled citizens?

People with disability suffer segregation, face physical barriers hindering them in their access to the institutions, experience job discrimination and very often lack the opportunity for independent living and self-determination. The state's efforts must aim at restoring them to a status where

- they are able to obtain individualized assistance within the community rather than being secluded in a medical institution;
- they enjoy the rights of full citizenship and have access to all institutions;
- they have equal employment opportunities with the rest of society; and
- they have as much personal self-determination as possible, including independence from their families if they so desire.

These aims require a systematic pursuit of a bundle of policies. First and foremost, the model of what is considered as an adequate way of living for the disabled must be changed. In the distant past, something like an *informal support model* was dominant in Western societies. This model made the disabled person dependent on his/her family, friends, or neighbors for assistance. Later on, a kind of *medical model* took over. In this model, health care workers provide assistance to the disabled under the supervision of physicians and nurses. The goals and standards of the assistance are defined by the medical profession, not the disabled persons themselves.

Recently, a new model called the *consumer directed personal assistance model* emerged. Here, the disabled person takes the stage as a consumer who advertises for assistants and informs the job seekers of the requirements. In this last model, the disabled person obtains substantial control over the timing and manner in which services are provided to him or her. While in the medical model the disabled person fills the role of a patient, in this latter model he or she is a self-directed consumer of

services. Obviously, the consumer directed personal assistance model is strongly connected with the ideal of independent living and integration into the community.

The Rights of the Disabled

It is commonly agreed that no attempt at rehabilitating the disabled citizens to their status as equals of their fellow citizens can succeed unless equal rights are secured to them. There are three general methods of securing equality of rights: Anti-discrimination, Equal Opportunity and Preferential Treatment. Each method focuses on a different aspect of equality. Anti-discrimination combats disadvantaging based on an impairment, equal opportunity policy combats the inequalities of the starting position that reduce the life chances of the disabled people, while preferential treatment positively advantages the disabled so as to break the vicious circle from past discrimination through present inequality of opportunity to new discrimination. Most countries committed to furthering the rights of the disabled use a combination of the three approaches. The HCLU insists that, separately, the three approaches cannot achieve a real and sustainable equality. A combination of all three must be in place and enforced by the government.

Anti-Discrimination

The Anti-discrimination approach advocates a formal or judicial equality. It assumes that governments cannot or should not favor any group to the disadvantage of another one. It argues that outlawing discrimination is a sine qua non for having a society of equals. Anti-discrimination is a crucial step in ensuring equal rights. However, it is important to note that where discrimination has been systematically practiced in the past, anti-discrimination is not sufficient to restore equality.

There are two main types of discrimination recognized: Active and Passive. Active discrimination is when a person refuses to provide a service or a product to a disabled person because of his or her disability. For example, active discrimination occurs if a person, who is in all ways qualified for a job, is refused employment solely on the ground that he or she is disabled (whether or not the functional failing impedes him or her in discharging the duties of the job). In contrast, passive discrimination is the abstention from pro-active measures to eliminate barriers. Passive discrimination happens when a person with a disability is not able to access a service or product because barriers are not removed (e.g., no ramps and other facilities are put in place to facilitate the entry into a public building of a person reduced to a wheelchair). It is discriminatory to keep in place those barriers that limit opportunities for people with disabilities to access buildings and/or services. Most countries have some form of anti-discrimination law for people with disabilities, either in their employment, civil or criminal code. Sweden, Austria, and Switzerland are examples of countries that have anti-discrimination clauses specifically referencing people with disabilities.

Equal Opportunity

The equal opportunity approach recognizes that true equality can only exist if, beyond having equal rights, people also have equal starting conditions in their competition for career options. It argues that differences should not translate into disadvantages. It works to promote a society in which equal opportunities are presented to people with disabilities in terms of employment, access, and cultural and social events. However, equal starting conditions might not suffice for different peoples' opportunities to become truly equal. First, past discrimination might have cumulative effects in the present that are not eliminated by merely equalizing the

starting conditions. Second, the idea of equal starting conditions is ambiguous. Are the starting conditions equal when the access of external resources is the same, or do handicaps count in defining those conditions? This consideration leads to the approach of

Preferential Treatment

Preferential treatment focuses on results. It consists in disparate treatment that secures special advantages to a group (in our case, the disabled). Such disparate treatment needs justification. It is justified when

- the advantaged group suffers serious social handicaps that tend to reproduce themselves;
- the aim of the advantaging is to break the vicious circle of reproducing a social handicap;
- the policy of advantaging is effective, i.e., it has a chance to succeed in reaching this aim;
- the policy has no effective alternative that would bring about the same result without employing the method of preferential treatment; and, finally,
- the policy consists in temporary measures that make further application of those measures superfluous over time.

Preferential treatment has been used widely in Scandinavian countries and in the United States for gender and racial inequalities. It attempts to rectify discrimination by offering the victims of past exclusion advantages in areas such as employment, education, etc.

Similar to the equal opportunity approach, preferential treatment needs a strong state presence to implement and enforce measures. It sets up concrete

standards and measurements in which to gauge the level of equality within a society. Employment quotas are the most common example of preferential treatment for people with disabilities. Countries that have some form of employment quota system are France, Hungary and Germany.

What are the international standards?

The main international human rights documents, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights do not include any specific provisions on the people with disabilities.

Nevertheless, these documents can be successfully appealed to in the defense of the disabled. Even if their language does not mention “disabilities” or “disabled people”, their anti-discrimination provisions can be interpreted as applying to such people.

While the United Nations have adopted specific conventions on the rights of the children, on women’s rights or on the ban on racial discrimination, up to these days there has been no international convention adopted on the people with disabilities. But at least a *Standard Rules of Equalization of Opportunities for Persons with Disabilities* [Standard Rules] has been issued by the UN in 1993.

The Standard Rules sets up the guidelines for member states to implement policies equalizing opportunities. However, it is important to note that the guidelines are not compulsory. Each member state has the liberty and responsibility to decide for itself how to do justice to the ideals pursued by the Standard Rules. Article 24 of the Standard Rules defines equalization of opportunity as “the process through which various systems of society and the environment, ... are made available to all, particularly to persons with disabilities”. It urges member states to recognize that

people with disabilities have a right to access all institutional, economic and environmental resources of society and that these aspects should be made accessible, either through physical improvements such as wheelchair ramps or alternative formats (e.g., audio for the visually impaired, sign language for the hearing impaired, etc.).

Another important document that outlines equalization of opportunity is the Council of Europe's *Recommendation No. R (92) 6* (1992). It is a recommendation to member states for a coherent policy regarding people with disabilities. As a mere recommendation, it is not legally binding. It can, however serve as an important tool for local NGO's to evaluate their government's policy regarding people with disabilities. It spells out a coherent conception of the aims of the policies to rehabilitate the status of the disabled. These aims are securing independent living and access to assistance according to personal wishes; access to all institutions of society, right to full citizenship; economic independence; personal self-determination.

Several international documents include provisions prohibiting discrimination against people with disabilities or demanding preferential treatment of them. Thus, Article 13 of the *Amsterdam Treaty* (1999) and *Protocol 12 to the European Convention on Human Rights* (2000) are Europe's major anti-discrimination clauses. The *Amsterdam Treaty* (that revised the *Maastricht Treaty* of 1992) is the European Union's main legal instrument. In the original Maastricht Treaty there was no mention of people with disabilities. Article 13 of the Amsterdam Treaty, the anti-discrimination clause, specifically mentions people with disabilities. It should be noted, however, that Article 13 does not allow the Union to adopt binding measures in all areas related to discrimination. Its scope is restricted to those areas where the Union has competence as defined by the Treaty. Thus, Article 13 applies to employment but has

no application to education or housing issues. Even so, it may provide the basis for new legislation, and may result in the European Court of Justice recognizing that the right not to be discriminated against applies to people with disabilities, as it has already hinted with regard to gender.

Article 14 of the *European Convention on Human Rights* (1950) is the clause dealing with discrimination. However Article 14 ensures anti-discrimination only to the rights laid out in the *Convention*. “The enforcement of rights and freedoms *set forth in this convention* shall be secured without discrimination” (emphasis added). Article 14 does not guarantee general protection from discrimination. There were calls to broaden the jurisdiction of Article 14. In 2000, *Protocol 12* was enacted and ratified with the purpose of strengthening the *Convention’s* guarantees with regard to equality and non-discrimination. Article 1 of *Protocol 12* lays out that the “ The enjoyment of *any right set forth by law*, shall be secured without discrimination on any grounds” (emphasis added). Article 1 of *Protocol 12* broadens the scope of the original Article 14 and makes protection against discrimination a general right. Instead of only being applicable to the rights in the *Convention* it is applicable to all rights guaranteed by national laws.

Protocol 12 does not require states to take positive measures to combat discrimination, rather it focuses primarily on a negative obligation: states are bound to refrain from discriminating against individuals. However, the duty to ‘secure’ may imply a positive obligation if there is an obvious gap in domestic law. For example, *Protocol 12* mandates that member states prohibit to private persons conducting public activities (running a market venture, e.g.) from denying access to a restaurant or other public services.

A third document protecting people with disabilities from discrimination within the European Union is the *Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation*. It seeks to establish a fair employment arena and is a legally binding document for all member states. Article 5 deals exclusively with reasonable accommodation for disabled persons and states “employers shall take appropriate measures ... to enable a person with a disability to have access to, participate in, or advance employment.” This directive helps to create an employment arena in which the disabled community ceases to be a burden on the able-bodied community, dependent on benefits and allocations from charity funds and government subsidies. Instead they become an integral and tax paying force within the community.

What has been done?

In the last two decades there has been a lot of activity by disability organizations to ensure equal opportunity. There are many global movements on part of the disabled population, and HCLU would like to highlight two. The first was the movement for the creation of the Americans with Disabilities Act in the United States. The second movement concerns European developments and is being directed by the European Disability Forum [EDF]. Both of these movements sought to incorporate and unite the disabled population to create strong regional forces.

ADA movement in America

The United States has a commendable civil rights law to protect people with disabilities: the Americans with Disabilities Act of 1990 (ADA). There are many

lessons to learn not just from the actual law itself but also the steps and procedures taken to put the law into place. The initiative for the creation of the ADA rose from the disabled community. Traditionally, people with different disabilities were categorized separately. Thus, there was little to no unity between people with physical disabilities and, for example, people with mental disabilities. The American disability community pushed to unite and include all people with various disabilities, from people who used wheelchairs to people diagnosed with HIV.

The ADA is a landmark act as it places disability discrimination on a par with race and gender discrimination. It serves as a basis for litigation against discrimination and other grievances suffered by disabled people. Court decisions, then, elucidate the content of the law and make the consequences of its provisions more specific.

In *Bragdon v. Abbot*, 1998 the Supreme Court affirmed that people with HIV/AIDS are protected under the ADA due to 'a substantial limitation on a major life activity'. In *Olmstead v. L.C.* 1999 it ruled that people with disabilities have a right to be integrated into the community. According to this decision, states must provide community placements for individuals with disabilities who are capable of living in the community; unnecessary institutionalization amounts to discrimination.

Later on, in *Garrett v Alabama* 2001, the Supreme Court declared that the a state cannot be sued for damages on the basis of the ADA. This ruling is related to the federal nature of the US constitutional system: according to the Eleventh Amendment of the Constitution, states enjoy immunity to the interference by the federal government, and special reasons are needed to abrogate that immunity. Thus, so long as a state's general policies towards the disabled are rational, that state is not required to provide the disabled with special accommodations. This ruling,

however, does not detract from the principles involved by the ADA; its purpose has to be understood as aiming to clarify the respective rights of a state and the federal government.

European Disability Forum

There are several disability organizations seeking the extension of the rights for the disabled in Europe. Established in 1997, the European Disability Forum [EDF] seeks to join different NGO's to present a strong and united front in Europe. It is made up of 66 European NGO's and 15 National Councils of disabled people from throughout the Member States. The EDF was a key player in the inclusion of people with disabilities in Article 13 of the *Amsterdam Treaty* (see above). It seeks to incorporate the disabled population in Europe and unite it to create a strong regional force ensuring that European laws take into account people with disabilities.

The EDF is committed to continuing the representation and battle for people with disabilities in the EU. It monitors and advocates the rights of people with disabilities in commissions and treaties that are established by the EU. The EDF is currently active in The European Year of the Disabled scheduled in 2003 (see website edf-feph.org) and is monitoring the Social Inclusion Action Program. A guide for campaigning has been published and is directed towards different European Disability organizations in an attempt to ensure the representation of people with disabilities within the Action Program. Both of these campaigns highlight EDF's commitment to integrating various disability organizations across Europe to present a united front within the European Union.

Hungary

Hungary has received praise for its comprehensive disability legislation. *Act No. XXVI of 1998 on The Provision of the Rights of Persons Living with Disability and Their Equal Opportunity* was awarded by the Franklin Delano Roosevelt Award in 1999. Under that Act, health care, education, employment, place of residence and culture are presented as target areas for the equalization of opportunity. Also established under the Act is the National Disability Affairs Council made up of government officials, people with disabilities and their representatives.

The Act also called upon Parliament to outline a program in which the above mentioned target areas would be altered. *The National Disability Program* was indeed designed to present the current social situation of people with disabilities and outline the tasks needed to bring about a change in social attitudes. The Program, published on December 10, 1999, also contains concrete deadlines for various target areas to ensure equal opportunity. It also requires that people with disabilities that are able to live independently be transferred from institutions to residential homes. It outlines the basic principles of disability policy including prevention, normalization, integration and self-determination. Positive discrimination or preferential treatment is argued to be an essential component in providing equal opportunity for people with disabilities.

Article 70/A of the Hungarian Constitution is Hungary's non-discrimination clause. It is not a general anti-discrimination provision because it prohibits discrimination only with regard to constitutional rights. But it has the potential to be interpreted by the courts expansively. This was tested in 1995 by a male wheelchair user who sued a bank which was only accessible through stairs. In a landmark case which set the precedent for future disability discrimination cases, the court held in favor of the litigant, arguing that it is discriminatory to fail in providing architectural

accessibility. Finally, Hungary recently passed a law that allows class action law suits to be heard in court. It is now possible for national organizations representing disabled people and the National Council of Disabilities to bring a case before the court. This right is no longer dependent upon an identifiable disabled person proving that he or she was victim of discrimination.

These legal developments notwithstanding, the social and institutional practice did not undergo a satisfying reform yet. Let us summarize the main findings.

Institutions

To these days, 18000 people with a disability are staying in nursing homes, while there are only 2000 disabled living in their own house and receiving day-care. There are no care centers in any significant numbers where disabled people could find temporary shelter. As a consequence, those persons with a disability who are not institutionalized, are taken care of mainly by their family, and the majority of such families do not find any assistance other than coming from a hospital.

Half of the nursing homes are of such a poor quality that they could not obtain any official license other than temporary. At the same time, disabled people make long lines to get into one of these homes; half of those waiting for admission applied for it more than a year ago.

The institutions for children with mental disabilities admit of 110 inmates on the average, the per capita room often falls below the legally mandated 6 m².

This is the starting position from where one ought to reach the target, set by *The National Disability Program*, to replace the large institutions for the disabled by small living homes until 2010.

Education

The National Disability Program prescribes that people with disabilities should have the opportunity to participate in an integrated educational environment. The National Disability Council funds an information center (Student Services) for students with disabilities attending higher education institutions. Nevertheless, to these days, of 250000 students enrolled in the higher education only 320 were disabled in the year 2000. That is less than 1 for 800. At the same time, there are about 500000 citizens with disabilities in Hungary for about 10000000 inhabitants. That is approximately 1 for 20. The disparity between the disabled people's education participation rate and their rate of participation in the population at large is enormous.

Another example of the gap between the incipient measures and the target to reach is related to elementary school education. In 1997, the Government created a public fund to assist the disabled schoolchildren in closing up with their healthy peers. In 1999, another public fund has been created for the rehabilitation of the disabled (Public Fund for the Chances for the Disabled). Still, 30% of children with a disability fail to finish their elementary school studies up to these days.

Employment

According to the census of 1990, the economic activity rate of the Hungarian population at large was 43.6% in that year, that of the disabled was 16.6%. The total activity rate decreased, since that time, by about 10%, that of the disabled by more than 10%. Thus, the gap was wide at the time of the transition from communism to democracy, and it widened further in the first decade of the new regime.

Structural accessibility

The Parliamentary Commissioner on Civic Rights recently issued a report based on a comprehensive inquiry about people with physical impairments. It analyzed the current status of structural accessibility in Hungary. The report argued that In the year

2000, people with disabilities were still voicing complaints of the massive barriers they have to face in their every day living. According to Act XXVI, the structural environment must be accessible by the year 2005. However, at the current pace, it will take at least 50 years before reaching that target.

Poverty

People with disabilities still make-up a large portion of the population living under the poverty line. Recently, the Parliament decided that allocations to severely disabled people are to be raised from the former 50% to 65% of the minimum pension. The reason for the higher percentage is that the former figure amounted to a total less than the current child support. The rise, of course, a move in the right direction. At the same time, its justification shows that the people with disabilities continue to be perceived by the political decision-makers mainly as dependent family members, on a par with the children, rather than citizens who need to be provided with the conditions of independent life. Even if a person with a disability was able to live on his or her own, with a personal assistant, economic limitations would force them to remain in the family

HCLU on Furthering the Rights of People with Disabilities

The state should be committed to:

- *Creating an accessible society:* Access is a crucial step in equalizing opportunity. It encourages independence and freedom of movement for people with disabilities. Creating accessible transportation and ensuring architectural accessibility begins the process of empowering the disabled community.

- *Ensuring an equal education:* It is the state's responsibility to provide equal education for all. It is also the right of parents to decide what type of education best suits their child. The HCLU advocates a policy of allowing parents of children with disabilities and family counselors to determine the best educational environment. An integrated educational system guarantees equal education. Most children with disabilities are capable of and benefit greatly from attending schools with their healthy peers and vice versa. A country's cultural and social norms are taught in the school system. The HCLU insists that the government remain committed to providing an integrated, and thereby ensuring equal, education.
- *Providing Fair Housing:* The central government and local communities must ensure adequate and fair housing opportunities for people with disabilities. As long as people with disabilities are denied housing either by prejudiced landlords or because of an inability to access apartments because of physical barriers, they will not be able to enjoy equal rights and freedom which the rest of the community have. Thus, it is the governments' responsibility to guarantee appropriate and accessible housing for those people with disabilities that are willing and able to live an independent life.
- *Promoting De-institutionalization:* Act No. XXVI outlined that current institutions must be gradually altered by the year 2010. The act also advocates that persons who are capable of independent living be transferred to residential institutions located in the community. However, progress in this area remains slow and resources are weak. The government must remain committed to the ideas presented in Act XXVI and create an environment where people with disabilities have access to independent living opportunities. In those cases where people are not able to live independently, the government should take active measures to

humanize current institutions to create an environment that promotes rehabilitation.

- *Guaranteeing Equal Employment Opportunities:* Employment of people with disabilities is of utmost importance in their successful integration into the able-bodied community. Rather than pursuing an extensive benefits program as the only aim of the government, money should be invested in creating an accessible working environment. This would not only begin the process of integrating the workplace, but also relieve the burden of social services from the rest of the community.