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**DISABILITY STUDIES IN HUNGARY**

*The paper, following the train of thought of the UN Convention on the Rights of Persons with Disabilities, is focusing on the development of disability studies in Hungary. Although Hungary was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities (2007), the human rights' based approach is still very weak, due to the weakness of the civil organisations, deficiencies of political democracy, and the party politics dominated permanent transition of the Hungarian welfare state. Disability studies, characterised internationally by the initiative of the disabled persons themselves, were in Hungary, however, a top-down process initiated by researchers and experts. This is reflected in the controversies and slowness of the deinstitutionalisation process, in the dominance of large institutions and in the exclusion of disabled adults from the labour market, instead of the implementation of community based solutions. Governmental approaches and policies are first and foremost targeting economic objectives, e.g. to decrease the budgetary deficit even at the expense of the living conditions of disabled people. The official rhetoric and the organisational solutions have not broken away from the medical model of disability yet.*

*Key words: United Nations, rights, civil society, employment, independent living, deinstitutionalisation.*

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**ŠTUDIJ HENDIKEPA NA MADŽARSKEM**

*Članek prikaže razvoj študija hendikepa na Madžarskem. To je tudi priporočilo Konvencije Združenih narodov o pravicah invalidov. Čeprav je bila Madžarska ena prvih držav, ki je omenjeno konvencijo leta 2007 ratificirala, je pristop, ki temelji na človekovih pravicah, tam še vedno le šibek. Vzroki za to so šibkost civilnodružbenih organizacij, pomanjkljiva politična demokracija in strankarska politika večne tranzicije madžarske države blaginje. Študij hendikepa, za katerega je v mednarodnem prostoru značilno, da so ga razvijale osebe z ovirami, je na Madžarskem doživel obrnjen proces, ki so ga uvedli raziskovalci in strokovnjaki z vrha navzdol. To se kaže v nasprotujočih si težnjah in počasnosti procesa dez-institucionalizacije, v katerem prevladujejo velike institucije in izključitev oseb z ovirami iz trga dela, namesto da bi bile implementirane v skupnosti utemeljene rešitve. Vladni pristopi in ukrepi zadevajo predvsem ekonomske cilje, na primer zmanjšanje finančnega primanjkljaja, celo na račun življenjskih razmer oseb z ovirami. Uradna retorika in rešitve se še niso oddaljile od medicinskega modela oviranosti.*

*Ključne besede: Združeni narodi, pravice, civilna družba, zaposlovanje, neodvisno življenje, dez-institucionalizacija.*

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**Introduction**

Disability studies were defined by the Hungarian Association of Disability Science (Eötvös Loránd Tudományegyetem Bárczi Gusztáv Gyógypedagógiai Kar 2009) as follows:

Disability science is focusing on the policies and activities of societies to understand the far more social than physical experiences related to disability. Disability science was developed to unravel the phenomenon of impairment from the net of myths, ideologies and stigmas covering social interactions and social policy. This discipline disputes the idea that the social

and economic status of, as well as the roles assigned to disabled people are the inevitable consequence of their state of health.

This article intends to reveal the situation of disabled people by the analysis of the development of disability studies in Hungary. In our understanding disability studies is not a separate discipline locked in the cage of disability, but an umbrella conception approaching disability and the situation of disabled people based on the principles of the Convention on the Rights of Persons with Disabilities (007). In this paper, the principles of the respect for individual needs (independent living) and the problem of self-organisation (defence of interests, interest representation) are chosen as the guideline, and in three case studies (employment, deinstitutionalisation, and community based services) the realisation of these principles will be demonstrated.

## Historical perspective

### *Approaches*

The taproot of disability studies is nourished by the history of special education in Hungary, although its development, especially at the very beginning, was lagging behind the European processes in the field. The main stages of this history are the opening of the Royal Deaf and Dumb Institution in Vác in 1802 and the beginning of the so called institutionalised healing and educating of blind people in 1825. Before enacting the law on education initiated by József Eötvös in 1868 children with learning disabilities were generally excluded from the educational system and then, although just temporarily, educational obligation was extended to children with learning disabilities. In 1875 the first private educational institution for children with learning disabilities was opened and in 1896 the state took over the First Educational and Nursing Institution for the Mentally Retarded.

In the 19th century – as elsewhere in Europe – the new discipline was located at the crossroad of medical science and pedagogy. As a result of the significant German influence, special education gradually incorporated ideas from social sciences and psychology. (Mesterházi 2004)

First, experts in special education were trained abroad and in the 1890s employees of the institutions of special education were trained at special courses in Hungary. The world famous Hungarian special education was launched in the predecessor of the Bárczy Gusztáv Faculty of Special Education, the Teacher-Training College of Special Education at Vác for the further education of primary-school teachers in 1900. (Gordosné 2010.)

After the turn of the century the system approach broadened the scope of special education. As Zoltán Tóth (1933) stated: in the education of disabled children not only the educational protection but social protection gets more and more importance and the whole scope of activities and organisations of disability related issues are an integral part of special education.

After the Second World War it was hard work to maintain the values and achievements of special education as the communist ideology considered it to be bourgeois ideology and incompatible with the socialist ideal of human beings.

The theoretical and practical activities of Gusztáv Bárczi, being himself a practitioner in special education, saved Hungarian special education. His outstanding research results made him known to the politicians, and as a skilful organiser and diplomat he reorganised the discipline under the cover of the conditioning education of Pavlov and thus special education could preserve its complex and multidisciplinary approach to human beings. (Bánfalvy *et al.* 2004)

The price of survival was the isolation of special education and the domination of the medical approach in the functioning of its institutions. Although the leading experts in the field applied a complex and multidisciplinary approach to disability, the profession was still confined to the basic institutions of public education and social protection for decades. Early child development, community based services, career counselling, rehabilitation of adults and several other issues were not institutionalised.

Another part of the root is embedded in the development of institutions of political democracy and human rights. Before the systemic change, in the period of soft dictatorship, rarely, and mainly in the papers of researchers, appeared ideas like independent living, normalisation and complex rehabilitation. The majority of disabled children were trained in segregated institutions of special education; adults, due to the lack of accessibility and alternative forms of living, frequently lived in huge institutions of residential care; employment of disabled persons, if it was possible for them at all, was realised at special work places.

Innovative approaches exceeding the medical model of disability gradually became more and more popular among the professionals. However, systemic, paradigmatic changes were not introduced. Rather, the innovative initiatives were incorporated into the existing structures. Decision makers argued with the utmost importance of economic problems when referring to the reasons for delays to changes in the field. (Tausz, Varjú 1991.)

According to Verdes (2009), a different explanation has to be given. According to him, the large institutions had two functions during the transition. On one hand they made these socially excluded groups, among them the disabled people, invisible, and on the other, large institutions of residential care mitigated the burden of unemployment as these provided work for masses of people.

Consequently, until the appearance of the human rights based approach and the idea of deinstitutionalisation, individual needs were overridden by other types of interests.

### *Mainstreaming*

Although Hungary was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities in 2007, the human rights' based approach is still very weak. Complex reasons explain the survival of the medical approach, and the weakness of the social model: among others the fragility of the culture of democracy and the 'permanent transition' of the Hungarian welfare state.

Because of their importance, two pieces of legislation will be emphasized: Act XXVI of 1998 on ensuring equal opportunities for persons with disabilities and Act CXXXV of 2003 on Equal Treatment and Promotion of Equal Opportunities, which approach the problems related to disability and the situation of disabled persons in accordance with the European standards.

Although the Disability Act and the first National Disability Program were great leaps forward, these are based on a mix of values and approaches. According to its intention the Act follows a system based approach, but uses the medical model to determine the target group (the type and severity of disability). It shows traces of the human rights based model, referring to the rights of disabled persons when outlining the target areas. And indirectly, when initiating institutionalised state intervention in several areas, especially in the National Disability Program, it intends to enlarge the chances of social participation.

On the basis of Act XXVI of 1998 on ensuring equal opportunities for persons with disabilities, Hungary formulated the first disability programme in 1999, which was in force till 2005, and then a second programme was adopted in 2006 and in force till 2013.

The national programmes of disability affairs specified the responsibilities of the state in different fields (Universal Design, rehabilitation, positive change in the attitude of society towards people with disabilities, deinstitutionalisation, employment etc.), however, both versions are preliminary concepts rather than concrete, enforceable measures and their objective is to improve the quality of life of disabled persons instead of the realisation of the human rights of disabled people and guaranteeing law enforcement.

The development is rectilinear just on the surface, considering practical measures taken in the different fields. A detailed critical description of the problems would exceed the limits of this paper, but the controversies will be delineated in the three case studies.

Even though it disappeared from the legal rhetoric, governmental policies of the past years, first of all the so called reform of the disability benefit system, seem to warm up the approaches of the moral model when arguing for the necessity of changes with referring to the misuse of the disability qualification system and to the scroungers.

While before the change of the political system, with some exceptions, issues discussed in the discipline of special education dominated researches and activities related to disability and the situation of disabled people; after the transition it moved in the direction of social sciences studying human as well as social relations of disabled children (Illyés 2000).

More and more research was carried out on the possibilities of social integration, the toolkit of affirmative action and on the social situation of disabled people. Previously the college of special education was the most important centre for this research. Recently however, sociologists, social workers, social policy experts, economists and legal experts also deal with the subject all over the country. Despite the more and more lively scientific activities in the field, disability studies appeared as an autonomous discipline just after the ratification of Convention on the Rights of People with Disability. In 2008 the Bárczi Gusztáv Faculty of Special Education organised the Research Group on Occupational Rehabilitation where lectures were delivered on the subject for a larger audience for two years and three volumes of the new Disability Studies journal was published. After the change of the government in 2010 financial resources were withdrawn, terminating this programme. However, interdisciplinary research on the situation of disabled persons continued and disability studies became integrated into the mainstream sciences.

A similar process is characterising developments of higher education: courses on the situation of disabled people are integrated into the education of social workers, social policy and minority studies experts.

### *Concepts*

A dual picture is the starting point of any models of disability: the good and the stigmatised, the healthy and the sick, the socially integrated and the excluded, a person with legal capacity and the one deprived of it. This duality presupposes two general actors subordinated to each other. Recognising the oppression of disabled people and the basic findings of the social model of disability more and more attention is paid to the disabled individual, to the individual needs, to the personal experiences and intentions of disabled persons in the latest research and policy development initiatives in Hungary.

Anomalies of the social model, its rigidity, its transitional character and tightness, the numerous frequently contradictory fragmented approaches of it prove this model is also inadequate to reveal the complexity of disability as it looks for the possibilities of understanding mainly in the intellectual and physical environment. Thus this model is unable to clarify the complex interrelationships between power relations, cultural contexts, discourses and the personal experiences related to disability. (...) It is mistaken when approaching disability just as a macro level social problem, as, among others, the personal experience, the personal struggle and the pain are also constitutive factors of disabled existence. (Köncei, Hernádi 2011.)

### **Role of the civil society**

Spreading and functioning of the majority of the non-profit organisations - with the exception of the politically neutral ones, like the sport clubs, or the Patriotic People's Front and the trade unions created and influenced by the political power – was impeded by the one party political system as well as by the economic structure (e.g. the lack of free self-organisation and a market economy, the monopoly of the state in providing public services) before 1989. Therefore development of the non-profit organisations after the end of the 1980s significantly diverged from that of the countries with a democratic political system. (Bocz 2010.)

Organisations representing disabled people and organised according to the type of disability (National Federation of Disabled Persons' Associations – 1981, Hungarian Federation of the Blind and Partially Sighted – 1918, Hungarian Association of the Deaf and Hard of Hearing – 1907, Hungarian Association for Persons with Intellectual Disability 1981) were embedded into this structure.

Formation of the political democracy and the market economy resulted in a dynamic development in the non-profit sector as well: in 2012 more than 65 thousand civic and other types of non-profit organisations worked in Hungary.

Some of the civic organisations already existed before the political changes and have continued their activities in more or less the same fields and forms (recreational, cultural and sport activities), while others set new objectives and followed new forms of operation (*ibid.*).

Organisations representing disabled people gradually developed to be real pressure groups. Some groups of disabled people, like people with psycho-social disability or people with autism, who had no targeted interest representation in the past, created their own pressure groups and organisations. As a response to the lack of resources and using the benefits of the taxation system some non-profit organisations also provide services. For instance, under the umbrella of the large residential institutions, foundations are functioning to narrow the gap between financial resources given by the state and the costs of functioning, e.g. by subsidizing programmes, supplying new instruments or contributing to the costs of a new group home. Non-profit organisations providing services frequently supplement the lacking services provided by the state and apply innovative solutions. The government also launched quasi non-profit organisations, like the Public-benefit Nonprofit Company for the Equal Opportunities of Persons with Disabilities. Although a complex system of legal regulations regarding disability and disabled persons exists in Hungary, its gaps, and difficulties in the assertion of their rights, led to the activities of, among others, the Hungarian Civil Liberties Union, a human rights watchdog.

Most of the non-profit organisations for disabled persons came into existence as a result of a top-down process; however some of the non-profit organisations are based on real civic initiatives, like the Association of Independent Living, the Association of Voice of Soul or some consumer run projects.

Hungarian and international authors agree that governmental policy may to a large extent encourage or hinder the spreading of non-profit organisations and their functioning as service providers by the conscious shaping of the institutional and legal framework. Indirectly (e.g. by tax allowances) and directly (e.g. by providing financial resources and properties) the government may facilitate or restrain their functioning and future development. The quality of cooperation between the government and the non-profit sector is characterised by the nature of involvement of non-profit organisations in the procedure of reconciliation of interests: either they are handled as real partners or just as symbolic supporting actors during the decision making processes. (Bocz: 2010.)

In this respect stormy movements characterise the non-profit sector. At its formation, a serious role was assigned to the National Disability Committee by the representatives of the government and disabled people. However, after enacting the law on the equal opportunities of disabled people the Committee lost its significance in recent years. The National Disability Committee has had no regular meetings since the change of government, although by law, as the advisory body of the government it ought to be convened quarterly. The so called public debate system withered in the past years; although the bills and other types of legal regulations are published, consultation with the interested parties is formal, mainly restricted to the possibility to send opinions to a website. Several organisations representing disabled persons protested against the communication breakdown and not involving disabled people into the process of legislation affecting the living conditions of disabled people.

The system of reconciliation of interests between the government and the civic and non-profit organisations is characterised by instability; governments and ruling parties strived to create institutional structures providing a more favourable operational environment for organisations 'closer' to them. (*Ibid.*)

## Right to rehabilitation and employment

The Act on the rights of persons with disabilities declares the right to rehabilitation, the implementation of which – also according to the Act – would be provided by rehabilitation benefits and services.

One of the problems was that the issue of rehabilitation was delegated to a public foundation in 1998, which could never have been able to run a nationwide operating rehabilitation system.

In the past sixteen years a complete rehabilitation system on all stages of life and in all sectors, adequate for neither the Convention on the Rights of Persons with Disabilities rehabilitation approach nor for the definition of rehabilitation of the World Health Organization or International Labour Organization was built up.

The need for complex rehabilitation is reflected both in the concepts and in setting up some services (rehabilitation residential facilities and group homes), but in these places effective rehabilitation leading disabled persons back to the community and preparing them for independent living is very rare. A similar situation exists in the public education field, where different schools of special education were established (early childhood intervention, primary schools and vocational education), but these institutions insufficiently prepare young people for work and independent living.

The most serious problems occur in the employment of disabled adults. The employment rate of working age people with disability is 13.4 percent, while their inactivity rate<sup>1</sup> is 74.2 percent (Hungarian Central Statistical Office 2001). The Hungarian labour market is characterised by shrinking work-intensive and widening knowledge-intensive sectors, which excludes people with a low level of education and generates oversupply on the market. In this demand-oriented and knowledge-intensive competition people who have a low level of education and are stigmatised as persons with altered working capacity hardly have any chance to get a job.

Another serious symptom is that more than 50 percent of people with altered working capacity<sup>2</sup> have no other choice than to claim some form of disability benefit, because they either have no job, or their earning is so low that it does not ensure a decent living.

Hungarian legislators have not even been touched by the human rights based approach of disability studies when formulating the system of disability benefits. Evaluating the impact of disability benefits on social security one has to reach the conclusion that budgetary difficulties due to the economic crisis were alleviated by cutting benefits, targeting persons in the most disadvantageous situation and by demolishing the social safety net.

The official rhetoric for communicating the changes uses panels of the radical right differentiating the deserving and the undeserving poor. Soon after getting into power the first news was released on the misuse of disability pensions and on the 'disproportionate number' of claimants.

Referring to the misuse of benefits, a comprehensive review was ordered and restructuring of the complete disability benefit system had begun to make the qualification process tighter. However, the main objective of the so called reform was to reduce expenditures on disability benefits (Janecskó 2011.)

The more rigid procedure was introduced from 2010 to 2011. The same doctors, civil servants and social workers run the so called complex committees assessing the working capacity of the claimants and assigning the subsidies to people with altered working capacity. Statistics of the National Office for Rehabilitation and Social Affairs reveal significant changes in the level of social insurance based benefits rather than in the number of beneficiaries.

The number of disability pensioners under the retirement age decreased to 305,323 persons by 2011 from the 422,695 persons in 2009. These changes were mostly due to the transformation

<sup>1</sup> Persons neither included in the employed nor in the unemployed category are classified as not in the labour force (also known as inactive).

<sup>2</sup> The term 'persons with altered working capacity' covers not only disabled adults, but persons with long term sickness as well.

of the qualification system and the new legal regulations targeting the disability benefit system, as a result of which fewer new entrants are admitted into the disability benefit system and several persons lost their right during the re-examination process.

The 'new' disability benefit system was introduced by the Act CXCI of 2011 on the benefits of the persons with altered working capacity. According to the Act committees responsible for the qualification process have to review the previously issued certifications (approximately 250 thousand persons), however neither the infrastructure nor the number and the expertise of the staff have been developed, just the qualification guidelines tightened again.

The Act does not take into consideration the Convention on the Rights of People with Disability at all. As opposed to the previous form it gave up the human rights based approach, which is a withdrawal to the medical model. The previous system assessed the working capacity as well, while the recent one solely focuses on the health condition of the disabled person and the professionals' labelling lay the basis of entitlement for the benefits.

The above mentioned Act terminated the formerly existing forms of disability benefits and recently it has not only been the Pension Fund which finances the disability benefits, but the Health Fund. Consequently, not disability pensions, but health subsidies are provided. Persons formerly provided with disability benefits and the new claimants are divided into two groups: in one of them are those who have the chance for rehabilitation and in the other those who allegedly cannot be rehabilitated. Thus not only the nature of the transfer income has been changed, but the amount became significantly lower as well. This concept of rehabilitation is opposed to the wording and spirit of the CPRD and deprives people with altered working capacity from the right to rehabilitation.

Refuting government communication, the number of beneficiaries increased to 450 thousand persons again in 2012, just the composition of this group became more homogeneous and the level of the benefits decreased, endangering the beneficiaries with the risk of getting into poverty.

The real intentions of the government are reflected in the changing level of expenditures on disability benefits. The difficulties of the Hungarian labour market are frequently attributed to the extremely high level of inactivity, the crisis of the pension system to the burdens of financing early retirement schemes. Actually, the real-value of the expenditure on disability benefits is decreasing. The number of people eligible for disability benefits did not significantly change, just state expenditure in the field decreased, consequently the same beneficiaries are provided with lower benefits.

Although all the professional preconditions have been given to implement the right to rehabilitation since 2002, and on the surface the government supports the implementation of the Supported Employment and Back to Work occupational rehabilitation programs based on American and British schemes, the lack of unambiguous political commitment hinders improvements in the field. Although up-to date knowledge and more than ten year's experience on the procedures of complex rehabilitation is available in Hungary, this know-how is not adopted by the state run services of rehabilitation.

However, several non-profit organisations realise the intention of the CPRD as they provide complex rehabilitation services for the service users. The average success rate, e.g. the integration of disabled people into the labour market is far higher than that of the governmental organisations. This high success rate proves services taking into consideration personal needs are far more effective than uniformity.

### **Right to independent living**

Transition from institutional care to independent living is a good example of people with disability gaining back their right to make decisions about their own life on an equal basis with other citizens. Supported living complemented with community based services can be the basis of independent living.

In Hungary social services for people with disability are still institutionally based. In 2010 16,668 people with disability lived in residential care; 11,939 of them lived in institutions with more than 50 beds and 72 percent of housing services were institutional based (Hungarian Central Statistical Office 2010.)

Throughout history different factors influenced the philosophy and practice of residential services in Hungary. In the 1950s the pedagogical principles of Makarenko, the logic of the state-socialist regime and the availability of real estate contributed to the formation of residential services. Later the technocratic approach focused on the optimal size and on rational maintaining. By the sixties the smaller residential homes were amalgamated so the large institutions became the mainstream. Although in the eighties the new ideas reached the professionals and experts, the structure of the services was not transformed; rather the new approaches were inserted into the existing structure.

The paradigmatic change came in 1998, when the idea of deinstitutionalization (DI) first appeared in the Hungarian legislation. Hungary ratified the Convention on the Rights of People with Disability in 2007, but the first call for an EU funded project proposal in connection with DI was advertised only in 2009 – but with controversial content. It would have allowed the building of institutions of up to 150 beds. Fortunately this plan has never been realised because of the joint efforts of the civil organizations. The final call for proposals appeared in 2012 and the deinstitutionalization process started in 2013. The idea of deinstitutionalization is based on the Convention on the Rights of People with Disability, specifically on Article 19, which maintains the right to live independently and be included in the community.

States party to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

If we talk about deinstitutionalization we have to define the word institution as well.

The Guideline of the European Expert Group on the Transition from Institutional to Community Based Care defines institutions with three characteristics (Ministry of National Resources 2012):

- It isolates users from the community/society and forces them to live in cohabitation.
- Users do not have sufficient control over their own life and over the decisions that affect them.
- Institutional requirements take precedence over users' individual needs.

It considers institutionalization as a violation of human rights. The Guideline refers to the Report of the Ad Hoc Expert Group on the transition from institutional to community-based care. This report describes the size of a residential service as an important aspect of the complex definition of institution. According to it a high number of residents living together can increase the development of institutional culture. It considers residential services with more than 30 beds institutions (European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities 2009.)

In contrast, the current Hungarian legislation considers an institution a residential service with more than 50 beds and allows building 'living centres' up to 50 beds involved in the DI process. So there is a risk that in the first period of deinstitutionalization in Hungary small institutions will be built against the interest of the residents (Bugarszki *et al.* 2013).



The whole DI idea is based on the human rights based approach but this idea meets a structure based on institutional care and the medical approach in Hungary. So this structure is resistant to the human rights based approach in many ways. It is not a surprise that the directors and the staff of the large institutions and the local governments where the large institutions operate are the most resistant to the DI process. These stake holders play a key role in the DI process because they transform the large institutions, where they currently work, into supported living, consequently these actors have power to shape the whole DI process. The transformation of their medical approach into a human rights based approach is crucial. (*Ibid.*)

The DI process and specifically the composition of the DI Committee can provide a 'good' example of the decision making process in social policy in recent Hungary. The DI Coordination Committee could work as a space for discussion but the composition of the Committee strongly depends on the government as it delegates the members. Some crucial actors are missing from the DI Committee, for instance the real decision makers, human-rights NGOs and a wider representation of people with disability. DI is co-financed by the EU and the Hungarian government. The DI proposal writing process is a good example for the power of the institution's staff. The basis of the DI process was a complex needs' assessment of the residents managed by independent experts, which could have ensured that the DI is based on the needs of the residents. However, the four interviews made within the Deinstitutionalization Budget Monitoring Project by the Bugarszki-Eszik-Kondor research team with the directors of the institutions proved the final proposals were rather based on the experiences of the staff. (*Ibid.*)

As DI is partly financed from the EU Structural Fund, Brussels passed several recommendations to the government. One of these is the involvement of the stakeholders in the decision making process, with special attention to disabled people and their advocates. (European Expert Group on transition from institutional to community based care 2012.)

Table 1: Stakeholders of the deinstitutionalization, 2013.

	<b>Strongly supportive</b>	<b>Slightly supportive</b>	<b>Strongly against</b>	<b>Slightly against</b>
<b>High capacity to pressure</b>	State run service providers; Human-rights oriented NGOs	Ministry and minister of Finances, Advocacy organizations of disabled people	Directors and staff of the large institutions, Decisions makers of the local governments where the institutions are operating	Ministry of Human Resources, Government, Local governments affected by the DI, median voters, Church run service providers
<b>Low capacity to pressure</b>	Residents and their family members, institutions of higher education, EU			

The role of the Coordination Committee is the professional control of the DI. Their greatest success is that although the current legislation would allow building living centres with a maximum of 50 beds during the first period of DI, in conformity with the approach of the EU, housing services with a maximum of 30 beds will be built. (*Ibid.*)

Advocacy organizations of people with disability delegate four people to the Coordination Committee, which has fourteen members. They have high capacity to pressure the process but

they are not uniformly dedicated to the approach of the Convention on the Rights of People with Disability and the Guideline so they are considered to be weakly committed to the DI process. Some of these organizations are not only advocates but service providers as well, so they depend on the government, which is partially financing them. Since these organizations represent people with disability their unambiguous commitment to the DI would be essential. (*Ibid.*)

The non-profit human-rights NGOs like the Hungarian Civil Liberties Union and the Mental Disability Advocacy Centre have an important watchdog role in the process. The events of 2009 showed the key role of the HCLU when they united the civil organizations to prevent the building of institutions with a maximum of 150 beds in the framework of DI. (*Ibid.*)

The increasing importance of the social model is reflected in the composition of the Co-ordination Committee, as not only the Faculty of Special Education, but the Faculty of Social Sciences represents higher education institutions as well. The DI process reflects a paradigm shift from the medical and institution based approach to the human rights based model emphasizing the importance of the principle of independent living. However, the strength of the opponents of the DI increases the risk of the survival of the institutional culture and the chance that the rights of people with disability will be neglected.

### **Respect for inherent dignity, individual autonomy and freedom to make one's own choices**

A comparative research programme (Estonia, the Netherlands, Hungary) to develop new knowledge for professionals about effective components of community support programmes was carried out between 2012 and 2013 with the active participation of two of the authors of this paper. The objective of the research project was to facilitate the empowerment and self-support of persons with psycho-social and other disabilities.

The Hungarian team started its activities by challenging the meaning of community in this context. In the social protection system the meaning of community is to provide services in group homes and day centres in the local community instead of the large residential institutions. According to our understanding the 'smaller' institution and the services organised in the local community represent the first step, but just the first step ahead as these are still institutionalised forms of support.

A participatory action research design was used as the empirical component of the research. Personal and focus group interviews were held with the service users, with relevant members of their network and with professionals.

To reveal the components of the possible second step and to counterbalance our affinity to criticism, good practices and successful cases were chosen to answer the research questions. The partners were non-profit organisations and persons with psycho-social disability who were successfully integrated into some natural human network that is some form of human community.

We found that community-based services are key actors in the process of recovery and in facilitating the evolution of vivid human relationships.

While we tend to believe that the most relevant help arrives from professionals in the process of recovery we usually underestimate the impact of the informal community. We found that users often prefer public places instead of professional services because they are more integrated, less clinical and they provide a wider range of opportunities to create a new identity beyond mental health care. Local pubs and restaurants, a circle of friends, religious or hobby related groups, neighbourhood friends, colleagues and schoolmates are the natural resources for all of us and these resources usually provide a variety of possible new identities and life. (Community Support Project 2013.)

The recovery of people with psycho-social disability is a long and complex process. Personal needs based measures have to be applied for it to be a success. However, the lack of social housing and flexible work opportunities are serious obstacles to recovery. Managerism, strong

dependence on the financial resources provided by the state budget, as well as the officially encouraged anti-poor attitudes and the increasing denial of those who are different push social workers into an unacceptable situation. Social work education ought to react to these phenomena and renew the curriculum to make professionals able to cope with the situation.

The language and meaning is still frequently derived from the medical profession.

Service providers most of the time are forced to use a rather clinical language as the official language of the service. This is reflected many times in the name of the services, in their entire administration and even in the spoken language they use. Clinical language creates a distance between service users and professionals where the power of narration is obviously in the hand of professionals. On the other hand, one of the key elements of recovery is the opportunity to create a new, personal narrative. To promote the success of this process we need to create space for new languages and narratives within our settings, allowing users to develop their own narratives. (*Ibid.*)

This is the only possible way to demolish the duality of the healthy and the sick, the 'normal' and the deviant. To take possession of the language is one of the significant components of being the master of our own life.

And last but not least, even though prejudice against disabled people decreased in the past years, significant differences can be observed in this respect between the different groups of disabled people. According to the interviews people with mental health problems from time to time face neglect and rejection in society.

But we found some good examples when this could have been changed. Changes came when real encounters could happen and the qualities of the person overrode the stigma of mental health problems. (*Ibid.*)

## Conclusions

International disability policy changed enormously in the past ten years, however, the underlying principles of the Hungarian legislation and professional practice did not develop at an adequate speed. Although significant positive changes were initiated (legislation, beginning of deinstitutionalisation, innovative approaches of the non-profit organisations etc.) negative turns also occurred (changes in the disability benefit system, stigmatisation of people with altered working capacity, etc.). Disability Studies generally developed by the initiative of the disabled persons themselves, however, in Hungary this was a top-down process initiated by researchers and professionals. The human rights based disability policy could still not break through the barriers of the medical profession, changes in the social sector are too slow and the direction of the changes is controversial.

## References

- Bánfalvy, C., Szauder, E., Zászkaliczky, P. (2004), *Gyógypedagógus történetek*. Budapest: Bárczi Gusztáv Gyógypedagógiai Főiskola.
- Bugarszki, Z., Eszik, O., Kondor, Z. (2013), Deinstitutionalisation in Hungary 2012–2013. Available at: [http://tatk.elte.hu/dokumentumtar/cat\\_view/772-intezmenyi-kivaltas-tanulmanyok](http://tatk.elte.hu/dokumentumtar/cat_view/772-intezmenyi-kivaltas-tanulmanyok) (10. 3. 2014).
- Convention on the Rights of People with Disability (2006). Available at: <http://www.un.org/disabilities/default.asp?id=150> (10. 3. 2014).
- Community Support project (2013), *Budapest report. Description of project*. Available at: <http://www.communityparticipation-hu.nl/CmsData/Reports/Budapest%20Report%20Community%20Support.pdf> (10. 3. 2014).
- Bocz, J. (2010), A nonprofit szektor magyarországi működését befolyásoló tényezők. *Statisztikai Szemle*, 88, 4.
- European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities (2009), *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*. Available at: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes> (10. 3. 2014).

- European Expert Group on transition from institutional to community based care (2012), *Common European Guidelines on the transition from institutional to community based services*. Available at: <http://deinstitutionalisationguide.eu> (10. 3. 2014).
- Eötvös Loránd Tudományegyetem Bárczi Gusztáv Gyógypedagógiai Kar (2009). *Fogyatékoságtudományi fogalomtár*. Available at: <http://mek.oszk.hu/09400/09410/09410.pdf> (10. 3. 2014).
- Gordosné, S. A. (2010), *110 éves a gyógypedagógus-képzés Magyarországon*. Available at: [http://www.prae.hu/prae/gyosze.php?menu\\_id=102&jid=348&jaid=504](http://www.prae.hu/prae/gyosze.php?menu_id=102&jid=348&jaid=504) (10. 3. 2014).
- Hungarian Central Statistical Office (2001), *Population Census 2001*. Available at: <http://www.nepszamlalas2001.hu/eng/volumes/12/tartalom.html> (10. 3. 2014).
- (2010), *Bentlakásos szociális intézményi ellátás*. Available at: <http://statinfo.ksh.hu/Statinfo/haViewer.jsp> (10. 3. 2014).
- Illyés, S. (ed.) (2000), *Gyógypedagógia alapismeretek*. Budapest: ELTE BGGYFK.
- Janecska, K. (2011), *Korrupció nélkül nem menne a rokkantnyugdíj család*. Available at: [http://index.hu/belfold/2011/06/08/korrupcio\\_nelkul\\_nem\\_menne\\_a\\_rokkantnyugdij-csalas](http://index.hu/belfold/2011/06/08/korrupcio_nelkul_nem_menne_a_rokkantnyugdij-csalas) (10. 3. 2014).
- Könczei, G., Hernádi, I. (2011), A fogyatékoságtudomány főfogalma és annak változásai. In: Nagy, Z. É. (ed.), *Az akadályozott és az egészségkárosodott emberek élethelyzete Magyarországon*. Budapest: NCSSZI.
- Mesterházi, Z. (2004), A gyógypedagógia elméletképzésének főbb irányai. In: Zászkaliczky, P., Verdes, T. (ur.), *Tágabb értelemben vett gyógypedagógia*. Budapest: ELTE BGGYFK és Kölcsey Ferenc Protestáns Szakkollégium (17–65).
- Ministry of National Resources (2012), *Kiváltás a fogyatékos személyek ellátásának jövője*. Budapest: Nemzeti Erőforrás Minisztérium.
- Tausz, K., Varjú, G. (1991), „Neki is kell cukor?” / Néhány gondolat a szociális intézményekről és a fogyatékos emberek helyzetéről. *Esély*, 3, 5: 73–77.
- Tóth, Z. (1933), *Általános gyógypedagógia*. Budapest: Magyar Gyógypedagógiai Társaság.
- Verdes, T. (2009), A ház az intézet tulajdona. A totális intézmények lebontásáról, humanizálásáról és modernizálásáról. *Esély*, 4. Available at: [http://www.esely.org/kiadvanyok/2009\\_4/05verdes.pdf](http://www.esely.org/kiadvanyok/2009_4/05verdes.pdf) (10. 3. 2014).