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Informal Networks, International Developments and the Founding of the First Interest-Representing Associations of Disabled People in Hungary in the Late Socialist Period (1970s–1980s)

ABSTRACT

The article focuses on the grassroots activities of disabled citizens in Hungary during the recent socialist period and relates to the emergence of the first two interest-representing organisations, the National Association of People with Physical Disabilities and the National Association of Parents of Children with Mental and Intellectual Disabilities in 1981. By contextualising the disabled people's activities within the state socialist system, the article also contemplates the broader question if and to what extent it is possible to speak about a "social movement" and how the Hungarian disabled people's activities compare to those of disability rights movement participants elsewhere in the world. With regard to the specific traits of the Hungarian case, the article emphasises the crucial role of informal networks. Moreover, it argues that contrary to other (capitalist) countries where the efforts of self-determination were directed against the patronising attitudes of medical and professional experts, disabled activists in Hungary were actively and wholeheartedly assisted in their emancipatory desires by these professional groups. Last but not least, the article points to the significance of international connections and accommodates the activities of Hungarian disabled people within international developments and particularly within the increased activities in several countries during the International Year of Disabled Persons (1981).

Keywords: *Disability Movement, Hungary, Informal Networks*

Introduction: Background and Context

From the 1960s in the United States and later in other democratic countries, representatives of the disability rights movement started to raise their voices against the marginalisation and even stigmatisation of disabled citizens. They sought to empower disabled people to take control of their own lives and wanted to influence social

policies and practices in order to advance the integration of disabled people into the mainstream of society.¹ They expressed dissatisfaction with charitable foundations and established the first organisations which were run by disabled people themselves. This new emancipatory agenda also marked a shift in the understanding of disability: whereas earlier it was perceived as a medical category focused on the deficient body, participants in the social movement claimed that disability was in fact a social construct.²

But can we speak about a comparable movement or at least an initiative under state socialism? Could disabled citizens exercise their agency in authoritarian states where a free public sphere was absent? It is only relatively recently that this question has been posed by scholars working on the history of disability.³ Certainly, agency and self-determination may not be the most obvious concepts that people would associate with such societies. Instead, one might expect passivity and conformity; partly because of what is often – however unjustifiably – considered the limiting effect of disability, and partly because of the restrictive milieu of an unfree society. Moreover, another reason why research on bottom-up movements comprised of disabled groups has remained typically scarce may be the lack of reliable evidence. Unlike the abundant and usually well-organised archival material concerning political history, documents on health and welfare issues often bypassed the archives altogether, but even when they were archived, they usually ended up gathering dust in unsystematised piles. Traces of grassroots activities are even scarcer because they often took place in unofficial settings.

This article tells the story of the emergence of the two first grassroots associations of disabled citizens in late socialist Hungary: the National Association of People with Physical Disabilities and the National Association of Parent of Children with Mental and Intellectual Disabilities. Using the example of Hungarian disabled people and their supporters under state socialism it discusses how it was possible to exercise self-determination under certain circumstances and it also points to the significance of informal networks and arrangements in the strategies of interest-representation. In a

- 1 Jerry Alan Winter: *The Development of the Disability Rights Movement as a Social Problem Solver*, in: *Disability Studies Quarterly* 23:1 (2003), pp. 33–61, available online at: <http://dsq-sds.org/article/view/399/545> (accessed on 23 October 2014).
- 2 See Paul K. Longmore/Lauri Umansky: *Introduction: Disability History: From the Margins to the Mainstream*, in: Paul K. Longmore/Lauri Umansky (eds.): *The New Disability History: American Perspectives*, New York/London 2001, pp. 1–32, 20.
- 3 For a treatment of disabled people's grassroots and dissident activities in the Soviet Union see William O. McCagg/Lewis Siegelbaum (eds.): *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, Pittsburgh 1989. For the case of dictatorships in Spain and Latin America see Gildas Brégain: *An Entangled Perspective on Disability History: The Disability Protests in Argentina, Brazil and Spain 1968–1982*, in: Sebastian Barsch/Anne Klein/Pieter Verstraete (eds.): *The Imperfect Historian: Disability Histories in Europe*, Frankfurt am Main et al. 2013, pp. 133–154.

more general context, the article also seeks to unravel certain common tendencies with other socialist and capitalist countries, as well as assessing any trajectories which might have been special to the Hungarian case. Moreover, it calls attention to the existence of relatively regular transnational connections between leaders of disabled people's organisations in Hungary and in Western Europe.

In order to be able to evaluate the significance of Hungarian disabled peoples' grassroots activities during the 1970s and the 1980s, and to assess the extent to which they formed a movement comparable to their counterparts elsewhere in the world, it is necessary to examine the conditions under which they performed their actions. Anglo-Saxon scholarship on the disability movement has criticised the harsh and repressive attitudes towards disabled citizens in the capitalist system,⁴ and the same can be said about its socialist counterparts. The importance of the strong, healthy body and employment performance was equally important in both systems and the capacity to work was the primary criterion for social entitlement. Disabled people who could not contribute to the national economy were not considered full citizens and were eligible for fewer benefits. They were also typically exposed to isolation and pity. Yet, a significant difference was that, unlike in established democracies, under authoritarian regimes alternative viewpoints were typically silenced and independent organisations of disabled people were usually not permitted.⁵

Grassroots initiatives typically responded to the deficiencies of existing social policies and practices. Therefore, an obvious point of departure for contextualisation may be an overview of socialist governance, legislation and welfare policy. In addition to providing a useful background, such an overview also demonstrates that these policies were neither unchanging nor universal. Rather, their nature was informed both by international and national developments. The academic literature on social policies typically divides state socialism into three chronological phases.⁶ These periods were not identical in every state socialist country, but were nevertheless informed by similarities. The first phase involved the period from the communist takeover until the early 1960s, the second one lasted until the mid-1980s and the third one until the systemic changes of 1990. These phases correspond to early, classical and late state socialism and in all the three phases – to varying degrees – welfare measures were used as instruments that contributed to the legitimation of the government.

4 See Jane Campbell/Mike Oliver: *Disability Politics: Understanding our Past, Changing our Future*, London/New York 1996.

5 See Michael Rasell/Elena Iarskaia-Smirnova (eds.): *Disability in Eastern Europe and the Former Soviet Union: History, Policy and Everyday Life*, London 2014, p. 7.

6 Dorottya Szikra: *Social Policy under State Socialism in Hungary (1949–1956)*, in: Sabine Hering (ed.): *Social Care under State Socialism 1945–1989: Ambitions, Ambiguities, and Mismanagement*, Opladen 2009, pp. 141–148, 142.

The structure and mechanism of social policy in the first phase was characterised by tremendous political and economic transformation, both in the socialist countries. In Hungary it coincided with the Stalinist regime of Mátyás Rákosi and the coming into power of János Kádár, who became the first secretary of the Communist Party, after the suppression of the revolution in which he played the major role, in 1956. Rákosi's Stalinist regime in the first half of the 1950s required total commitment, it was characterised by the maxim "whoever is not with us is against us". Moreover, the regime rejected the bourgeois welfare tradition. According to a widely accepted definition, the primary aim of social policy is to counterbalance the inequalities stemming from competition in the free market. Through the redistribution of resources, social policy contributes to social integration and fosters feelings of solidarity.⁷ Therefore, the absence of a free market and freedom of expression makes it difficult to use the term "social policy" in its traditional sense. In fact, in the 1950s, Hungarian officials assumed that the predicted economic growth, based on the socialist relations of ownership, would eliminate all kinds of anomalies and social policy would be rendered obsolete. Accordingly, not only was the term "social policy" banned from the official vocabulary, but even the existence of the Ministry of Social Welfare was deemed redundant, because welfare was expected to occur naturally.⁸

Kádár's system lasted from 1956 until 1988, the year before the fall of the communism. It therefore ranged from the classical to the late stage of socialism and these periods saw the "return of social policy" to the political agenda. Following the brutal suppression of the 1956 revolution, Kádár's regime was installed through Soviet political and military intervention. The regime harshly punished many of those involved in the revolution, but was aware that political stability could not be ensured by coercion alone. Consequently, Kádár was compelled to try to consolidate society by offering concessions to Hungarian citizens. On the ideological front, the state no longer required explicit political compliance as long as people did not actively resist the regime. Thus, in contrast to the Stalinist regime of Mátyás Rákosi in the early 1950s, the *modus vivendi* in the post-1956 consolidation period became: "whoever is not against us is with us". Consequently, people were generally allowed to conduct their lives as they

7 See Richard M. Titmuss: *Social Policy: An Introduction*, London 1974, pp. 23–32. On Hungary see Robert Manchin/Iván Szelényi: *Social Policy under State Socialism: Market Distribution and Social Inequalities in Eastern European Socialist Societies*, in: Gosta Esping-Andersen/Lee Rainwater/Martin Rein (eds.): *Stagnation and Renewal in Social Policy: The Rise and Fall of Policy Regimes*, New York 1987, pp. 102–135. Moreover, a book by Lynne Haney: *Inventing the Needy, Gender and the Politics of Welfare in Hungary*, Berkeley/Los Angeles 2002, gives an insight into the gender-related aspects of social policy under state socialism.

8 See Zsuzsa Ferge: *A Society in the Making of Hungarian Social and Societal Policy 1945–75*, New York 1979, pp. 63–64.

wished, with a greater degree of individual initiative and negotiation than in other socialist countries. It was even possible to openly criticise the practices of the system, although not its principles.⁹

From the 1960s onwards, as the ideological ruptures in the system became increasingly evident, social policy gradually started to reappear in the socialist countries. A contemporary Hungarian bureaucrat justified this reversal in the following way: “the socialist system could not and cannot solve every societal problem at once or in a short time; therefore, the existence of social policy cannot be qualified as “anachronistic”.”¹⁰ The term *socialist* historically meant that the regime legitimised itself by claiming to provide a more humane alternative to the policies that were customarily pursued in societies dominated by the market forces. In some ways the institutions at the heart of the socialist welfare state were systematically positioned against their Western counterparts.¹¹ There is no doubt that social policy constituted a field of competition during the Cold War. To that purpose, a report produced by the bureaucrats at the Social Policy Department of the Hungarian Ministry of Work in 1973 stipulated that:

it is necessary to improve the prestige of socialism against capitalism, even under the current circumstances when the economic development of socialist countries is still significantly lagging behind that of capitalist countries [...]. In our social policy we are still searching for a particular field in which our socialist society can offer something extraordinary to the workers, even at this early stage of development. We are looking for something which will make us trailblazers and which makes socialism really socialism.¹²

- 9 Literature on Kádár and his regime includes János M. Rainer: *Bevezetés a kádárizmusba* (Introduction to Kádárism), Budapest 2011; Tibor Huszár: *Kádár János politikai életrajza* (János Kádár's Political Biography), Budapest 2006 and Roger Gough: *A Good Comrade: Janos Kadar, Communism and Hungary*, London 2006. On Hungarian economical history see János Kornai: *Economics of Shortage*, Amsterdam 1980; Nigel Swain: *Hungary: The Rise and Fall of Feasible Socialism*, London/New York 1992.
- 10 József Berényi: *Életszínvonal és szociálpolitika* (Living Standards and Social Policy), Budapest 1974, p. 87.
- 11 See William O. McCagg/Lewis Siegelbaum (eds.): *The Disabled in the Soviet Union: Past and Present, Theory and Practice*, Pittsburgh 1989, p. 4.
- 12 Recommendation by the Department of Social Policy on the long-term planning of social policy, prepared for the meeting with the Deputy Minister, 2 April 1973 cited by Sándor Horváth: *Két emelet boldogság: Mindennapi szociálpolitika Budapesten a Kádár korban* (Two Floors of Happiness. Everyday Social Policy in Budapest under the Kádár Regime), Budapest 2012, p. 50. The author did all Hungarian translations in the article.

The relationship between the regime and the population during the post-Stalinist period has often been likened to a social contract. This meant that citizens had to give up their freedom of expression and were expected to comply with the regime. In return, they could expect generous social benefits and economic security, which included full employment, heavily subsidised prices for basic goods as well as free education, medical care and child care.¹³ It is indicative that in Hungary, social benefits reached such a generous level that, by the 1980s, they constituted one-third of people's incomes.¹⁴ In this context, a concept of "welfare dictatorship", which had originally been employed in the case of the German Democratic Republic, may be relevant as it indicates that welfare measures constituted a very powerful legitimating principle for the state.¹⁵

Kádár's consolidation strategy sought to depoliticise citizens by diverting their interests from politics and encouraging their retirement into the private sphere.¹⁶ Placating tactics included the improvement of living standards, the extension of welfare measures, the widening of travel opportunities to the West, and the relatively generous provision of consumer goods. However, all of these could only be supported by an increasing reliance on foreign credits and as a result, the state came perilously close to bankruptcy in the early 1980s. Nevertheless, despite these problems, Kádár's politics of consolidation proved remarkably successful. Hungary emerged as the merriest barrack in the Eastern bloc and Kádár's "goulash communism"¹⁷ came to enjoy substantial societal support.¹⁸

The successes and failures within the welfare policy reveal certain common tendencies in the socialist countries. Significant achievements included a comprehensive health system, extensive childcare and recreational opportunities. On the other hand,

13 See Linda J. Cook: *The Soviet Social Contract and Why it Failed: Welfare Policy and Workers' Politics from Brezhnev to Yeltsin*, Cambridge 1993.

14 See Sándor Horváth: *Két emelet boldogság: Mindennapi szociálpolitika Budapesten a Kádár korban*, p. 51. Paradoxically, however, the redistribution by the state did not help to create a more egalitarian society, but further contributed to the growth of social inequalities. See Sándor Horváth: *Két emelet boldogság: Mindennapi szociálpolitika Budapesten a Kádár korban*, p. 67.

15 Konrad H. Jarausch: *Care and Coercion: The GDR as Welfare Dictatorship*, in: Jarausch (ed.), *Dictatorship as Experience: Towards a Socio-Cultural History of the GDR*, New York/London 1993, pp. 47–72.

16 See András Körösnéyi: *Government and Politics in Hungary*, Budapest 1999, p. 24.

17 See Tamas Dombos/Lena Pellandini-Simanyi: *Kids, Cars or Cashews?: Debating and Re-membering Consumption in Socialist Hungary*, in: Paulina Bren/Mary Neuburger (eds.): *Communism Unwrapped: Consumption in Cold War Eastern Europe*, Oxford/New York 2012, pp. 325–350.

18 See Mary Fulbrook: *The People's State: East German Society from Hitler to Honecker*, New Haven 2005, p. IX.

it is generally acknowledged that the groups of the disabled as well as elderly people in need of support were neglected and excluded rather than reasonably supported. This was because the state was not willing to reconcile the interest of minorities with those of a greater community.¹⁹ However, it is possible to say that these groups also received insufficient treatment in established democracies. Such insufficiency was the very reason for disabled people's activities and movements both in Hungary and elsewhere and in this context, the International Year of Disabled Persons which was organised by the United Nations (UN) in 1981 and endorsed disability as a *human rights issue*²⁰ provided an important impetus as a legitimating force of existing and emerging movements alike. Just as importantly, the International Year became a catalyst for politicisation. This was because the official rhetoric associated with the event raised expectations significantly. Nevertheless, these expectations could not be met in a period which coincided with a major financial crisis in post-war history, which had its origins in the oil crises of the late 1970s. In the financial context, a similar pattern between the "capitalist West" and "socialist East" has been noted in academic literature: the constant growth of public expenditure, inclusive of welfare expenditure in the 1970s, and the crisis of the welfare state in the 1980s.²¹

Frequent meetings and an intensive exchange of ideas were typical of this period and – in addition to the transnational networks of medical experts, politicians and policymakers – for the first time disabled people themselves started to contribute to those exchanges, forming Disabled People's International, the first global organisation entirely run by disabled citizens whose headquarters were situated in Ottawa, Canada.²² Crucially for the purposes of this article, the formation of the National Association of People with Physical Disabilities and the National Association of Parents of Children with Intellectual Disabilities in 1981 in Hungary was directly inspired by the International Year. Further, the Year provided the final push for their official acknowledgement as negotiating partners of the state in matters of disability policy.

19 Sabine Hering: Introduction, in: Sabine Hering (ed.): *Social Care under State Socialism 1945–1989: Ambitions, Ambiguities, and Mismanagement*, Opladen 2009, p. 12.

20 See Theresia Degener/Yolan Koster-Dreese (eds.): *Human Rights and Disabled Persons: Essays and Relevant Human Rights Instruments*, Dordrecht 1995.

21 Dorottya Szikra: *Social Policy under State Socialism in Hungary (1949–1956)*, in: Sabine Hering (ed.): *Social Care under State Socialism 1945–1989: Ambitions, Ambiguities, and Mismanagement*, Opladen 2009, p. 141.

22 Diane Driedger: *The Last Civil Rights Movement: Disabled People's International*, New York 1989, pp. 33–36.

The National Association of People with Physical Disabilities

Just like in other countries, significant differences and hierarchies existed between different groups of disabled people in Hungary, depending on the cause and the type of their disablement. Blind and deaf people occupied a special position within the disabled community because they benefited from a long tradition of interest representation. The first organisation of Deaf and Hard of Hearing People came into being as early as in 1887. In 1901, another association was established with the intention to help blind people, while in 1918, the Association of the Blind was founded and this organisation was already initiated and governed by the blind people themselves.²³ Prior to the Second World War, veterans enjoyed the highest prestige, as they could use the powerful argument that they sacrificed their health in defence of the country. Contrary to this, in socialist Hungary veterans who became disabled during the Second World War were considered untrustworthy retrogrades who had fought on the “wrong side” – in alliance with Nazi Germany and against the Soviet Union. Consequently, they were marginalised rather than respected.²⁴ It is true however that under state socialism, leaders of their associations merely paid lip service to the idea of interest representation. Yet, the very existence of these organisations provided the framework and infrastructure which allowed their members to become mobilised and stand up for their interests on certain occasions. By contrast, other disabled groups did not get the opportunity to organise themselves until the late 1970s, and even then, as we shall see, their enterprise was merely tolerated, rather than genuinely supported.²⁵ This was not only because of political reasons, but also because, as has been mentioned above, people with disabilities did not fit in with the socialist ideal and were preferred to be kept away from the public eye.

The self-organisation of people with physical disabilities was rooted in a shared experience: many of them belonged to the polio victims of 1940s–1950s, who reached adulthood in the early 1970s. They got to know each other in the course of the extended periods of rehabilitation which was organised by the National Institute of Rehabilitation and Physiotherapy (ORFI), and took place in the so-called Heine-Medin rehabilitation pavilions which had been installed in the houses of the former bourgeoisie in a hilly and leafy district of Budapest. Here, as the former patients

23 See Vakok Szövetsége (ed.): *A vakok és gyengénlátók érdekvédelmének 60 éve*, Budapest 1978.

24 János Rithnovszky: *A fény túlsó oldalán* (At the Other End of the Light), Budapest 1991, p. 72

25 See Lajos Hegedüs: *Velünk élő történelem, avagy egy érdekérvényesítő polgári mozgalom mindennapjai* (Living History, or the Everyday Struggles of a Civil Rights Movement), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, pp. 135–175.

recall,²⁶ the aim of doctors, nurses and experts was not only to improve the medical condition of their patients, often with very basic technics and equipment, but also to create a community. The treatment and exercise rooms were characterised by a vibrant communal life, with debates, discussions and parties. A school was also attached to the medical establishment, where children and young people were given the opportunity to keep up with their education while away from their home environment and schools for several months. The majority of young people with polio-related disabilities spent extended time at least once or on more occasions in some of these institutions. For many of them, this was the sole opportunity during the year to enjoy social life, because otherwise in their ordinary environments the physical barriers – staircases, traffic islands, uneven pavement – prevented them from leaving the premises of their homes. As a result of this time spent together, friendships developed, love stories, often leading to marriages, evolved and these connections typically remained active for several years. All this reveals that the Heine-Medin rehabilitation pavilions were originally contact points from which new networks could develop, while they later also acted as knots which allowed for already existing networks to expand and cooperate. In that context they can be comparable to the communication networks of other social movements. For example, for the American civil rights movement churches and black colleges and for the youth movement university campuses fulfilled that role.²⁷ For the disability rights movement in several countries – once they became established – the independent living centres provided such contact points.

What frustrated many of these young people was that they experienced the impact of economic reforms in the late 1960s on the ambitious members of Hungarian society: they typically succeeded in obtaining new opportunities and improving their living conditions. By contrast, talented and ambitious disabled people were not able to benefit from these new opportunities because of their isolated status. Many of these young people with serious physical disabilities, if helped by their families, were able to pursue secondary education, some of them even studied at universities. They were already quite knowledgeable about the outside world (at least given their circumstances), and they did not want to accept isolation and helpless exposure to others as normal and unchangeable. It was clear to them that individually, or even with the help of their families, no matter how determined they were, they would not be able to overcome the existing obstacles. Cooperation therefore appeared to be a natural ambition, and it was also obvious that in order to be able to move forward, good connections with

26 *Ibid.*, p. 139.

27 Jo Freeman: *On the Origins of Social Movements*, in: Jo Freeman/Victoria Johnston (eds.): *Waves of Protest: Social Movements since the Sixties*, Oxford 1999, pp. 7–24; 9.

political dignitaries were also essential. Initially, cooperation was usually informal and directed at the solution of practical problems, but with time it developed into a more robust initiative which already carried (explicit or implicit) political overtones.

Virtually all disabled people who recalled the origins of the grassroots activities emphasised the generous support which they received from their doctors, physiotherapists and rehabilitation experts. This included advice and encouragement, but medical professionals also used their political and personal connections, as well as their professional reputation, to advance the interests of their patients. Just as their patients, doctors were aware that in the “Western world” grassroots initiatives of disabled people had become well-established and they actively motivated their patients to follow suit.²⁸ In the more relaxed atmosphere of the Kádár regime it was possible to find politicians who were supportive of the formation of disabled peoples’ organisations. What made things however complicated is that there existed no legal framework within which they could have functioned. Usually, the politicians who were supportive also helped to find legal opportunities, for example, by locating a paragraph of a statutory law issued by the Minister of Interior which could provide a point of departure. But the problem of the absence or insufficient nature of legal frameworks was not confined to the socialist system. In fact representatives of the disability rights movement in democratic countries also had to struggle either with the absence of legislation (often, there existed merely recommendations without legally bounding nature) or with the loopholes, waivers and exemptions in the existing legislation which made compliance and enforcement either difficult or impossible.²⁹

As we shall see, in the Hungarian case the founding of regional organisations did not prove overtly difficult, but when disabled people wanted to establish a more encompassing *national* organisation, in such a way that the regional associations retained their autonomy, the authorities were far from happy. It may not be surprising that the first grassroots initiatives came into being in the relatively innocent field of sport: in 1973 three disabled sport clubs were formed in the country. These proved successful, but it also became evident that tackling everyday problems required other forms of organisation. A crucial moment was the foundation of the first regional interest representation organisation in Northwest Hungary (Szombathely) in April 1977 with 67 members, with the director of the local library as its president. One of its founding members, a polio victim himself, Dr János Dalos had attended the annual meeting of the Hungarian Society for Rehabilitation four years earlier. During the event he

28 Margit Kurunzi Ficsorné: Az intellektuális fogyatékosággal élők emberek mozgalmának hazai története, in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 37.

29 Roberta Ann Johnson: *Mobilizing the Disabled*, in: Jo Freeman/Victoria Johnston (eds.): *Waves of Protest: Social Movements since the Sixties*, Oxford 1999, p. 27.

engaged in discussions with the participating doctors and health experts and they actively supported his idea to establish an interest representing association. In that year, also motivated by his frustration at finding employment as a disabled citizen, he contacted the Member of Parliament in his electoral district who was simultaneously the head of the Legal Committee of the Parliament. In the course of the discussion, the Member of Parliament mentioned that he had observed after travelling to the Netherlands, that disabled people there were much ahead in self-organisation. He expressed his belief that even in Hungary this was desirable and encouraged Dalos to work towards that goal, and also helped him with finding employment. The whimsical nature of the authorities' reaction to such initiatives becomes obvious from Dalos's observation that:

Perhaps surprisingly, given that influential politicians were so supportive in this case, the smaller rank bureaucrats were far from helpful. Ironically, one of them denied me permission to attend the inauguration meeting of the association of which I was a founding member. Upon the intervention of higher-ranking politicians I was finally allowed to participate and I spent the upcoming Easter vacation with typing ten copies of the statutes of the association on my small portable typewriter.³⁰

In Budapest, the first attempts to establish an association dated back to 1972. Disabled people received help from a former partisan who had good connections to the governing party, and even knew János Kádár in person (and who later became the first president of the Budapest association). However, the authorities rejected the idea with the excuse that a potential association would continue the work of the Association of Veterans (which was dissolved in 1948) and that it was not desired to give opportunities to the "retrograde veterans", nor to those injured during the "counter-revolution" of 1956.³¹ Five years later, in 1977, however, the second attempt was immediately successful. The founding document was signed by 13 people, including doctors, physiotherapists, sportsmen and a judge.³² In a Transdanubian region, in 1980 an announcement was placed in a local newspaper that a club for disabled people would be established in the local culture house. The response was overwhelming: even people from faraway places attended and this confirmed the organisers in their belief that their efforts had

30 Reminiscence of Dr. János Dalos, in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, pp. 140–141.

31 Reminiscence of Sándor Radnai, in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 141.

32 *Ibid.*, p. 141.

a rationale.³³ In East Hungary, in the city of Debrecen (the second largest city in the country), some local politicians were very helpful and in addition to a sport club with a sitting volleyball team which later even won championships, a small company was established in 1982 that was run by disabled people.³⁴ It is remarkable that on several occasions, such as in Southern Hungary, the local organisations were financially supported by the local companies (rather than by the state), they issued contracts which remained valid for unlimited time and which regulated the technicalities of sponsorship. On a subsequent occasion, a bank director awarded the fledging association the highest possible sum of money which he could offer on his own initiative, without prior consultation with his colleagues.³⁵ The nature of this kind of support is yet another indication of the crucial role of informal arrangements and also reveals that often no clear dividing line existed between official and informal procedures. Under state socialism in Hungary, private sponsorship in the strict sense of the word was not possible. It was possible, however, for factories and companies to make agreements with various organisations and offer them support in nature (voluntary work, materials, working tools) and occasionally in cash, in the framework of an arrangement which was typically referred to as a “socialist contract” between the two parties.³⁶

As has been hinted above, the authorities were more resistant to the desire to establish a *national* organisation of people with physical disabilities. By 1980 already ten regional associations had been formed, it was therefore not surprising that the desire to coordinate the wide-spread but hitherto isolated activities arose. The fact that Hungary had committed itself to work towards the desiderata of the International Year of Disabled Persons and that the need for autonomous associations of disabled persons was something to be taken for granted in the international arena would have made it pointless to prevent the formation of a national organisation altogether. All the more so, because the coordinating and preparatory committees for the UN-Year, which were formed at the regional level and which comprised doctors, experts and administrators, all wholeheartedly supported the cause. Under these circumstances the authorities tried to restrict and control the fledging association. For one thing, they wanted that

33 Reminiscence of Lajos Hegedűs, Lajos Hegedűs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 145.

34 Reminiscence of Dr Kálmán Gere, Lajos Hegedűs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 146.

35 Reminiscence by Dr Mihály Derrera, in: Lajos Hegedűs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, pp. 150–151.

36 In Hungarian the document was called “szocialista szerződés”. Its purpose was to detail the terms and obligations of voluntary work.

the new association became a branch of the Association of the Blind and Hard of Hearing People; they even offered them one or two paid positions if the members would accept the deal. This demand on the part of the authorities clearly sought to pacify the activists of the new association by placing them under the controlled auspices of an already existing organisation. Needless to say, this was not welcomed by the representatives of the freshly founded organisation, who found a successful tactic to deal with the situation: they claimed that they were not in the position to accept or reject such propositions because such decisions could only be made by the entire membership.³⁷ This reflects an important paradox in socialist legislation: on many occasions, in theory (or put another way on paper), the legal procedures in fact provided ample opportunities for people to make independent decisions at the bottom level. However, those who took such theoretical opportunities seriously and sought to introduce them into practice could have faced negative consequences. In this particular case, however, such references to the law could be employed to advance the interests of the promoters of the association.

The Minister of Health invited the representatives for a discussion, but they did not reach an agreement. He also wanted that all already functioning regional associations be dissolved and instead, one single, centrally-governed association be created, under the control of the Ministry. The disabled people refused this suggestion. Next, the Ministry expressed its willingness to the formation of an independent association (instead of becoming a branch of the Association of the Deaf), however, they still expected that the independence of the already existing regional associations come to an end and they merge into the national association. They once again categorically refused this condition and the discussions continued for another two months. These small details reveal the agency and empowerment of the disabled activists: they were ready to say no without any hesitation to the Ministry's dictates if they believed it did not serve their interests. One reason of this courage may have to do with a special agency of disabled people: the power of the powerless. This meant that when circumstances dictated, they could make use of their vulnerable status in order to attract sympathy or support. Moreover the fact that they had nothing or very little to lose could have also contributed to their empowerment.

An important micro-episode that once again reveals the power of personal connections and especially that of charismatic politicians revolves around the contribution of the highly popular female politician, the general secretary of the National Association of Trade Unions, Dr Judit Csehák, a physician by profession, to the legitimization of the disabled citizens' activities. An unusual phenomenon in the highest political echelons:

37 Reminiscence by Lajos Hegedüs, in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 147.

fragile, graceful, pretty and dressed with exceptional flair, even mentioning her name could sometimes help to open doors. This was surely because she represented a striking alternative to the typical appearance and behaviour of party cadres, who were almost exclusively men and are usually remembered as grey, nondescript figures. For example, when preparing for the inauguration meeting, one of the disabled organisers, who worked for the TV, managed to borrow a wireless microphone (which was in those days extraordinarily expensive), boasting that Csehák would also be present on the occasion. This worked like magic, he immediately received the microphone, all he was asked was to take care of it.³⁸ By this time the regional organisations numbered 19 and all of them had accepted the statutes which had been communally developed. When the inaugural meeting took place in June, 1981, the event was fully legitimate, with high-ranking politicians attending – among them the Deputy Minister of Health, Minister of Work (who was the head of the Committee for the International Year), and the above mentioned female politician. In the various speeches there was already clear support for the association, as it had always been considered a welcome and necessary development. One of the organisers recalls that:

To be honest, we were not aware of what we were doing. In order to avoid misunderstanding: we were neither anti-communists, nor anti-socialists, and we were not against the regime. We quite simply had enough of the situation that everything about us was decided above our head by ministries, bureaucrats and party people and we were never consulted. Only on one occasion, during a conference break in the spring of 1981 did it happen that a high-ranking party bureaucrat came to me and told me – of course, only face to face – ‘you bloody civil right activists, you will repent all what you are doing!’³⁹

Precisely because of the informal or semi-informal nature of these negotiations, it is not entirely clear what this party bureaucrat held against the association. It is very likely however that for some rigid cadres, the mere fact that the initiative challenged the existing status quo was already a sufficient reason for such a reaction. But this incident also testifies to another important phenomenon: namely that the authorities had no unified vision or strategy about how to deal with the emerging grassroots movement, and their reactions were often quite inconsistent and uncoordinated. This could be both advantageous and disadvantageous for the disability activists, depending on the concrete situation.

38 *Ibid.*, p. 147.

39 Reminiscence by Dr Mihály Derrera, in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 150.

Despite the initial problems – for example, the absence of proper legislation, which made it difficult to decide who is entitled to sign the various documents – it was a liberating feeling when the Association was assigned office space, even if the room which became their first “home” was run-down and difficultly accessible. Here, the various brochures and circular letters were typed and stenciled (back then, photocopiers in Hungary were not yet available) and these activities provided a great source of pleasure. Every single page of paper had to be accounted for by the Ministry of Interior, in order to prove that it was used for official purposes. Then, a company donated to the Association surplus rolls of paper which were not registered at the time of purchase, so they did not have to be accounted for. “We could write freely, whatever we wanted, and this was utterly liberating” – recalls one of the founding members of the Association.⁴⁰

Donations also started to arrive and not all of them were exactly useful, but with a sense of humour and certain resourcefulness nearly all items could be used for something. For example, among other things they included magazines containing the radio programme from the previous month filling half a truck, two trucks of pairless shoes (for one-legged people they should do!), shampoo (the first donation from abroad – from the cosmetics company Schwarzkopf), postcards with the image of the Lake Balaton (stained, from a warehouse). But no donations were ever refused, however useless. Members took the radio magazines to a collection point for recycling and they bought typing paper from the money they had received. They gave away the pairless shoes, the shampoo was used as a prize in sport competitions and the postcards which were in acceptable shape were sent with their greetings to the donors.⁴¹

International connections existed right from the very beginning, and even in this case, the significance of “moral capital” accumulated through informal contracts was enormous. An eager supporter and later the honorary vice-president of the organisation, Dr Pál Gadó, was a physicist and had an extended international scientific network which he wholeheartedly mobilised for the cause of forging international relations. At the first sight, it may perhaps be somewhat surprising that a non-disabled physicist offered his support in this way. At the same time, this episode is a useful reminder that people who promoted the association came from all walks of life. They were not necessarily disabled themselves and they might not have even had disabled family members or friends. Scientists with an international reputation had more extensive opportunities to travel abroad than the general public, in order to participate in congresses and conferences. Even if their direct networks might have not involved associations of disabled people, those networks could be extended in such a way that they reached out to disabled activists in foreign countries.

40 Ibid., p. 151.

41 Ibid., p. 152.

Soon bilateral connections were made with disability organisations in Austria, Switzerland, West-Germany, Italy, France and Finland. Thanks to these connections the Association became member of international networks such as the *Fédération Internationale des Mutilés et Invalides du Travail et des Invalides Civils* (International Federation of People with Physical Disabilities, FIMITIC), the European Disability Forum (EDF) and Disabled Peoples' International (DPI). The significance of these contacts was enormous:

We learned a lot from these connections. They helped us understand the concept of civil rights and human rights, interest representation, independent living, and tolerance, moreover, we also came to realise the importance of expertise. For those who spoke foreign languages among us, the world opened up because we received numerous invitations from the partner organisations. They paid all our expenses and also helped in a myriad of other ways.⁴²

Of special significance was the help of the Austrian Association of Civic Disabled, the German Reichsbund organisation (of War Veterans and Victims of Work Accidents) and the Swiss Association of Disabled Persons. They donated used medical aids to their Hungarian counterpart, paid for their conference participation, and above all, shared their knowledge with them.⁴³

Why was there so much interest in the Hungarian disabled people? One reason was that Hungary represented the unknown "Eastern world", but was at the same time was safe and relatively easy to visit. Those visits also brought to sharp relief that in Hungary barrier-free access, as a concept, barely existed, in fact, it was through these contacts that the Hungarian disabled people came to realise what accessibility actually meant and how that could be achieved. Moreover, on many occasions, they encountered for the very first time certain new medical aids and prostheses about the existence of which they had been fully unaware as the Hungarian health services could not afford to acquire them. They were also familiarised with the concept of independent living. A particularly successful event was the International Meeting of Disabled People at the Lake Balaton which was first organised in 1982 and thereafter every summer. These meetings were attended by 200–300 seriously disabled people from Austria, Switzerland, West Germany, Italy, Finland and of course, Hungary. Compared to European standards, the conditions which the Hungarian hosts could offer were extremely basic, guests were put up initially in a pioneer camp, later in a somewhat run-down hotel in Siófok, but the atmosphere was excellent. In addition to the guests from Western Europe, disabled people from the "brotherly socialist countries" (even

42 Ibid., p. 155.

43 Ibid.

from Albania) also attended these events.⁴⁴ The members of the Association received a lot of recognition for being able to function under such moderate conditions, and in 1986 they opened the Central and East European regional office of Disabled People's International in Budapest.⁴⁵ Further, several members were elected to important positions in the international organisations. As one of them concluded: "by the early 1980s, we achieved, at least in theory, that the authorities accepted our principle: 'nothing about us without us'"⁴⁶

The Association of Parents of Children with Mental and Intellectual Disabilities

People with mental and intellectual disabilities usually fared worse than those with physical disabilities. Families who looked after mentally ill members often felt ashamed and were isolated. The concept of racial hygiene and the tragedy of people with mental and intellectual disabilities under National Socialism was well known to the parents of disabled children and adults in Hungary, who detected certain parallels between the ways in which authoritarian states dealt with their "problematic members".⁴⁷ If physically disabled people felt that they did not fit in with the socialist aesthetics of the body, which was muscular, proportional and healthy, mental problems presented even more serious reasons for stigmatisation. It should not be forgotten, however, that the segregation of these "problematic" people was a standard practice of the age and medical and welfare arguments were engineered in order to ideologically justify it. In Hungary, only ten per cent of the mental health patients received professional, active treatment in specialised institutions, the majority of them were kept in establishments where no professional treatment was available.⁴⁸ In either case, typically, these were the old mansions and castles of former landlords in the countryside which had fallen into decay and were often seriously damaged during and after the Second World War. They were isolated even within their own micro-environments, surrounded by fields and forests and the buildings would have not been usable for any other purpose. This

44 Ibid., p. 154–155.

45 Ibid., p. 155.

46 Ibid., p. 156.

47 Margit Kurunczi Ficsorné: Az intellektuális fogyatékosággal élő emberek mozgalmának hazai története (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): A fogyatékosügy hazai és nemzetközi története (The International and National History of Disability), Budapest 2009, p. 37.

48 Péter Hajnóczy: Jelentések a sülyesztöböl: Az elkülönítő és más írások, Budapest 2013, p. 63. Originally, the text was published in the journal *Valóság* 10 (1975), pp. 66–92.

practice was by no means unique for Hungary (or even for the socialist countries). Often such institutions hosted a very heterogeneous group, including people who had no disabilities but were considered deviant for social reasons: war orphans, beggars, young prostitutes etc. Those who were institutionalised lived deprived of their rights, in a certain eternal child status, and invisible for members of the society. Contrary to proper active mental hospitals, where the status of the patients was regularly checked by legal representatives, no such practice existed in these nursing homes for the mentally disabled in Hungary, nor did they have the right to appeal against decisions. They were, in the strict sense of the word, in a lawless terrain. Similarly to other countries where young investigative journalists exposed these injustices, in Hungary the deplorable situation in these establishments was first brought to the light by a young writer, Péter Hajnóczy. He produced a sociographical account of the inhuman conditions in the largest nursing home of the country, close to the Western border.⁴⁹ His article which drew on that account and was published in the journal *Valóság* (Truth) in 1975 ignited a scandal, with serious repercussions for the writer and the editors.

The writer was taken to court by the director of the institution who claimed that he had never made the statements that the article attributed to him. However, the author was able to provide the audiocassettes which were recorded with the permission of the director, in order to provide evidence for his account. He also interviewed two doctors who had commenced their activities shortly before his visit; earlier on, patients were not examined or treated by specialists. Moreover, the article also included the story of a woman who had no mental problem but was nevertheless placed in the institution. This was not a singular case: people who were sent to those nursing homes were compelled to give up their apartments and once they arrived in the place, there was no opportunity ever to leave. Family members, acquaintances or people from work might have had an interest in acquiring these apartments and convince the unsuspecting vulnerable owners that they would have a better place in a nursing home. In the establishment which the writer described, people lived under deplorable conditions and were frequently terrorised. Moreover, the director operated a spy-system among patients and punished harshly whoever dared to complain. Even more shockingly, although he had no professional training and only elementary education, he considered himself in the position to treat patients, for example, by injecting drugs into their bodies, particularly as a way of punishment. All in all, the segregation, the absence of the public eye and the prejudices towards people with mental health problems rendered these establishment hotbeds of abuse.

49 The context is explained by Tamás Nagy in his foreword to Péter Hajnóczy's *Jelentések a sülyesztöböl*, pp. 7–29.

The outcome of the story of the Hungarian nursing home is indicative: on the one hand, the state vehemently denied the existence of any problem and the case had serious repercussions for the career of the writer who exposed the story. Yet, on the other hand, a comprehensive investigation was launched throughout the country.⁵⁰ As a consequence the lawless situation became rectified by the introduction of regular visits by doctors and legal representatives. It is likely that the case, which initially had had a professional dimension, evolved into a political scandal because the status of lawlessness could be interpreted not only in a concrete but also in a metaphorical way and in that context could be considered a criticism of the regime itself rather than just of certain medical and governmental practices.

But adults and children with mental and intellectual disabilities who stayed with their families were not necessarily in a much better situation. Just like in other countries, their parents – who often formed parents' associations – were the first to call attention to their problems. On their agenda were employment opportunities, rehabilitation, human rights and equal opportunities. In the 1970s the political climate as well as the international acceptance of disability as a human rights issue gradually allowed for the intensification of the activities. Just like in the case of people with physical disabilities, already in the early 1970s an attempt was made to establish an association. Parents and experts could make use of a law by decree which was passed in 1970, and one year later they asked permission from the Ministry of Health for preparation works for the foundation of an interest representation organisation.⁵¹ They argued that it would also be beneficial for the state, because the voluntary work of parents and experts could lead to the opening up of new employment opportunities. Although, as we shall see below, this first attempt was unsuccessful, some time later, in 1979, an advising bureau was launched and for the first time in Hungary and perhaps even in Eastern Europe, a holiday was organised for disabled people with intellectual disabilities aged 16 or over who lived with their families and were in employment.⁵²

50 Péter Hajnóczy: *Jelentések a sülyesztöböl: Az elkülönítő és más írások*, Budapest 2013, pp. 396–397.

51 Margit Kurunczi Ficsorné: *Az intellektuális fogyatékosággal élö emberek mozgalmának hazai története* (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009p. 41.

52 Speech of Károly Erdélyi at the Congress of the Hungarian Red Cross in 1981, reprinted in: Margit Kurunczi Ficsorné: *Az intellektuális fogyatékosággal élö emberek mozgalmának hazai története* (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 41.

Károly Erdélyi, a founding member of the National Association of Parents of Children with Intellectual and Mental Disabilities (ÉFOÉSZ⁵³) was initially the president of the parents' association of seven sheltered workplaces which came into being in Budapest in the 1960s-1970s. He recalls that one serious obstacle in their way was the fact that in the Soviet Union the authorities denied that disability was an "issue".⁵⁴ They claimed that they had no disabled population whose problems needed attention. As a result, every time he had a discussion with the Ministry, they confidentially informed him that until "such a thing" becomes established in the Soviet Union, they were not in the position to give permission to the "movement". In a polite letter, which arrived from the Central Committee of the Party, he was asked to discontinue with the organising activities, because the state was not financially able to handle the request anyway. If at a later stage the financial situation improves a solution would be found, he was told, because this was deemed to be the responsibility of the state. However, Erdélyi continued to write and write letters, and in the late 1970s the state bureaucracy gradually softened. As a result, the organisers of the association received permission to establish an advising bureau for parents within the premises of the Red Cross, the so-called "sub-committee of parents of children with intellectual and mental disabilities".⁵⁵

In the 1970s activists often referred to the existence of associations with the purpose of interest-representation of blind, deaf and deaf-mute people (even if that did not necessarily mean interest representation in reality) in order to exercise pressure on the authorities to establish a similar system for other disabled groups. The teachers of the College for Special Education, especially its then-director, Dr Viktor Göllesz, supported the idea from the very beginning, and a Member of Parliament, who was simultaneously the General Secretary of the Red Cross, also proved very helpful. Through this collaboration, in 1980 the Red Cross organised an exhibition of the drawings of children with intellectual disabilities in the building of the College for Special Education. Influencing public opinion was also an important task, and several articles and radio programmes were produced. It was however a television programme on the life of people with mental and intellectual disabilities, which was shown on Friday, 8 May 1980, – the world day of the Red Cross – that had the greatest impact because it reached out to a huge viewing public.

53 The original name of the association in Hungarian was *Értelmi Fogyatékosok Szüleinek Országos Érdekvédelmi Szekciója*.

54 Reminiscences by Károly Erdélyi, in Margit Kurunczi Ficsorné: *Az intellektuális fogyatékosokkal élő emberek mozgalmának hazai története* (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, pp. 38–39.

55 *Ibid.*, p. 39.

As we have seen, the partner association of physically disabled people was successful in its resistance to amalgamation within the National Association of the Deaf and Hard of Hearing. By contrast, the National Association of Parents of Children with Intellectual Disabilities (ÉFOÉSZ) could not avoid being temporarily made part of this association. Moreover, while the Association of People with Physical Disabilities achieved involvement in state-level planning, it initially refused to represent the interest of ÉFOÉSZ when negotiating with the authorities. ÉFOÉSZ not only sought to foster collaboration between families and institutions who were educating mentally and intellectually disabled people, it also strove to improve their educational and vocational opportunities and increase their quality of life, for example by organising cultural and sport activities. One of the founding members of ÉFOÉSZ, Éva Krausz, recalls:

Already in the 1960s I realised that children with intellectual disabilities will grow up and they will need to be looked after even when their parents have become aged or died. At the time of the founding of ÉFOÉSZ, I got to know several parents and it turned out that they were not prepared for the time when their children become adults. We established a club with these parents, where children and parents got together and simply had a good time. This club was run for several years with the help of volunteers. At the same time, we established an advising bureau for parents which were led by a lawyer and a special education expert. Thanks to the initiative of parents, a sports club was also founded. It was at the end of the 1980s that in the course of a club event for parents the first foundation, the so-called Shelter was established with ten members. Its aim was to gather money in order to buy a family house near Budapest where young people could try to live independently. All the activities, including the refurbishment of the house, were undertaken voluntarily. At that time, the initiators of the association were not yet aware that it is not sufficient to purchase a home; it would also need to be run on a long-time basis. But, as Ms Krausz recalls their principles were beautiful and truthful.⁵⁶

After the foundation of ÉFOÉSZ its regional branches came into being with extraordinary speed, thanks to the cooperation of parents and experts. Soon the entire country was covered and such an event was unprecedented in the “Eastern bloc”, because it entailed interest representation which was independent of the state. In 1985, the

56 Reminiscence by Éva Krausz, in: Margit Kurunczi Ficsorné: Az intellektuális fogyatékosággal élő emberek mozgalmának hazai története (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): A fogyatékosügy hazai és nemzetközi története (The International and National History of Disability), Budapest 2009, p. 40

magazine *Kapaszkodó* (Clinging onto) was founded and it remained the only significant medium which published its content – be it professional or aimed at the general public – also in simplified forms, so that it also becomes intelligible for people with intellectual disabilities. With its civil society approach, centring on the improvement of the opportunities of individuals, the Hungarian Association for Persons with Intellectual Disability was far more progressive than the paternalistic, medically centred approach which dominated the scene. They sought to build up regional branches, so the leaders visited every part of the country and by 1982 the process was completed. Every year the association organised holidays for 1,000 to 1,500 people. The Young Communists offered the Association to use their holiday resorts in Budapest and Debrecen for free. They received opportunities for nominal charges from the Army and the Trade Unions to spend time at the Lake Balaton. They were thus able to charge very modest fees for the holidays. The camps included sport and cultural opportunities and every participant received a memorial plate (produced by the Army). They collaborated with the Red Cross and several other suchlike organisations and also organised the first Day of the Disabled. Moreover, the association issued a special stamp which even became of special interest for collectors. A lavish full-day programme in the Operetta Theatre was also held and its income was distributed between four organisations.⁵⁷

From the outset of the Hungarian Association for Persons with Intellectual Disability established contacts with numerous international organisations of people with intellectual disabilities. They had frequent meetings with the Austrian partner organisation *Lebenshilfe* and they were able to send a representative to the meeting of the Council of Europe in Strassbourg. Another Austrian partner organisation, *Licht im Dunkel* invited them to its Christmas programme in 1991 and the activities and programmes of the organisation were presented in the TV show. One million shillings were received from the donations of the viewers, from which sheltered accommodation was established.⁵⁸ Importantly, the international organisations also provided a lot of moral support at the time when, after the fall of the regime in 1989, the association was unjustly attacked on

57 Reminiscence by Balázs Bujdosó, originally published with the title *Clinging Onto* in the special volume of the journal *Kapaszkodó* in 2009, reprinted in: Margit Kurunczi Ficsorné: *Az intellektuális fogyatékosággal élő emberek mozgalmának hazai története* (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 41.

58 Reminiscence by Miklós Lehel, originally published as *Mozgalmas és sorsdöntő esztendő* (Eventful and Decisive Year), in the special volume of the journal *Kapaszkodó* in 2008, reprinted in: Margit Kurunczi Ficsorné: *Az intellektuális fogyatékosággal élő emberek mozgalmának hazai története* (The History of the Movement of People Living with Intellectual Disabilities in Our Country), in: Lajos Hegedüs et al. (eds.): *A fogyatékosügy hazai és nemzetközi története* (The International and National History of Disability), Budapest 2009, p. 47.

several occasions, and became accused of being a remnant of the old regime, and not having a real membership. It is somewhat paradoxical that after all the efforts during the last decade of socialism, the Hungarian Association for Persons with Intellectual Disability had to prove that it was a real organisation with a membership of five to six thousand people, covering all parts of the country, in order to become involved in the preparation of the new legislation. The change of the regime also meant that the informal contracts which had been forged with the representatives of the old regime had been lost and in some ways, the lobbying for interest representation needed to start again, now with the representatives of the democratically elected government. The new system also came with new challenges, for example, the employment of disabled people became a special problem in the emerging free market, in which the previously existing social safety net had been lost.

Conclusion

The Hungarian disabled people's grassroots initiatives in the 1970s and 1980s reveal a considerable degree of agency. Like elsewhere, their activities were directed against official attitudes according to which disabled citizens were unable to take responsibility for their own lives. Thus, their guiding principles were in accordance with those of the representatives of the disability rights movement in other countries. It is true that their initiatives could hardly be classified as a social movement, given that their associations had formal status and a fixed membership. Nevertheless, it is worth remembering that the very definition of social movements in the context of disability has evolved in a very limited – predominantly Anglophone – context and this may render its applicability to other contexts questionable.

Moreover, the alleged spontaneous element of classical social movements should not be romanticised. It has been pointed out that the prerequisite for spontaneous activity and the rapid spread of a movement is an already pre-existing communications network or infrastructure within the social base of a movement. Even if there exists a large degree of discontent among the masses, unless they are linked in some ways they do not form a movement. In fact even for spontaneous protests to occur, the communications network must be well formed, as otherwise the initial interest will not survive.⁵⁹

On the whole, it appears that, while the Hungarian disabled activists were not in the position to exercise their agency in the same way as their counterparts could do in Western democracies, they were often able to achieve their goals by using their

59 Jo Freeman: *On the Origins of Social Movements*, in: Jo Freeman/Victoria Johnston (eds.): *Waves of Protest: Social Movements since the Sixties*, Oxford 1999, pp. 7–8.

informal networks and by making repeated attempts if they initially were unsuccessful. As we have seen, the authorities' attitudes were by no means consistent, and with some resourcefulness and patience, it was possible to find support in the highest echelons. The solidarity and support of foreign partner organisations also played a significant role in their success because, as we have seen, it contributed to the transfer of the know-how of interest representation as well as the values and norms of the international disability movement into Eastern Europe.

In capitalist societies disabled people were deemed to require permanent supervision by non-disabled experts. Charities often actively encouraged disabled people to assume a dependent role by compelling them to conform to the stereotype of helplessness, because their very legitimacy rested on the premise that their clients were dependent and incapable. Therefore, in the capitalist world disabled people wanted to liberate themselves from the patronising attitudes of professionals. In socialist countries, that paternalistic role was primarily performed by the state bureaucracy. It is therefore a particularly striking peculiarity of the Hungarian story that medical professionals actively and wholeheartedly supported the emancipatory goals of disabled people. They spent a lot of time and energy and made use of their connections as well as their professional reputation for the advancement of the disabled citizens' initiatives. The contribution of the Red Cross and of other bodies – including the communist youth organisation and the army is also noteworthy, as is the voluntary support of people who were not necessarily personally affected by disability. These organisations, at least to a certain extent, appear to have fulfilled functions that went beyond their mandate and that in democratic countries would have been performed by non-governmental organisations.

All in all, it appears that in the Hungarian case it was not a professional expert group, but the state and some of its institutions which represented the obstacles in the way of self-determination. Nevertheless, the success of the Hungarian disabled people's initiatives was at least in part due to the fact that the state failed to cater for the needs of every vulnerable social group. The activities of the new associations in fact covered blind spots in social policy and eased the state's burden in fields where it failed to live up its promises made to the citizens.

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