

Social Entrepreneurs and NGOs for People with Mental Disabilities in Post-Communist Europe: Implications for International Policy

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Abstract: Disability activists and disability non-governmental organization (NGO) leaders in post-communist Central Europe have been among the most instrumental force for promoting disability rights and community-based living initiatives in their formerly communist countries. During an on-going period of massive economic and political transition, these disability activists and NGO leaders managed to take advantage of emerging civil society freedoms and have established innovative models for the promotion of disability issues throughout the post-communist region. Of particular note are those initiatives that have addressed the needs of people with mental disabilities. The use of the term “mental disabilities” in this article refers to a diverse group of people who share the common experience of institutionalization due to perceived differences in emotion, perception, and/or cognition and who have faced longstanding barriers to community living in communist and post-communist Europe. The following article describes the national and historical contexts for people with mental disabilities in the Visegrad Four countries of Central Europe: Slovakia, the Czech Republic, Hungary, and Poland. It then highlights a number of innovative disability NGOs that are promoting human rights and community living for people with mental disabilities in each country. Implications for international collaboration with disability NGOs, and the importance of international disability policies, are discussed.

Key Words: Postcommunist; Disability NGO; Social Entrepreneur; Disability Policy

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Introduction

The Convention on the Rights of Persons with Disabilities and its Optional Protocol (United Nations, 2006) were adopted by the United Nations General Assembly in December 2006, and opened for signature in March 2007. Disability nongovernmental organizations (NGOs) were critical participants at this UN convention (Secretariat of the African Decade of Persons with Disabilities, 2007), and the final text of the convention emphasizes the importance of NGOs for promoting the involvement of people with disabilities in civic and public life across national contexts (United Nations, 2006). Previous initiatives focusing on international disability issues, such as the United States’ National Council on Disability (NCD) 2003 report, also called for greater attention to disability NGOs and the promotion of new ones as an important element in foreign policy and international development (NCD, 2003). The United States Agency for International Assistance (USAID) has indicated that the support of disability NGOs is consistent with the agency’s goal of strengthening civil society (USAID, 2003). Despite this apparent appreciation for disability NGOs and their role in international policy, however, little has been published about what these NGOs look like across different national and geopolitical contexts, what their priorities are within these contexts, or what makes some of them distinctive. The purpose here is to focus on the relevance of NGOs that are addressing mental disability issues in

a specific geopolitical region of the world, post-communist Central Europe. The goal is to bring attention to the history and context within which these disability NGOs are functioning, and then provide brief profiles of a number of NGOs in each of four countries so that concrete examples can be made apparent. The hope is that such a contribution to the literature will help provide a portrait of the current landscape for NGOs serving people with mental disabilities in this part of the world.

Source of the NGO Profiles

The profiles of disability NGOs offered here were gathered as part of a larger field study on disability issues in post-communist Europe. That larger research effort involved interviews with 17 key informant disability activists and NGO leaders in the Central European region. These key informants were selected according to criterion sampling. Criteria consisted of the following:

- 1) Informants must have been a founder or leader of a disability NGO;
- 2) Informants must have been perceived as a key figure by at least two experts outside their own NGO;
- 3) The NGO that the informant represented must have a presence in the literature, forums, or general discourse in the disability community; and
- 4) The informant had to be native to the Central and Eastern European region (i.e. not American, British, Scandinavian, etc.).

A number of different studies were drawn from the information gained from these key informant interviews with NGO leaders (i.e., Holland, 2008). The profiles provided here reflect a subgroup of the NGOs included in this larger field study. This subgroup was chosen for inclusion here for two reasons: a) they represented a good illustration of a variety of disability NGOs active in the region in terms of mission and priorities and b) they were engaged in some kind of particularly innovative effort with regards to disability issues.

The Focus on Mental Disabilities

This article focuses specifically on NGOs addressing the needs of people with mental disabilities in the four post-communist Central European countries of Slovakia, Hungary, Czech Republic, and Poland. This focus has been chosen for three reasons: (1) people with mental disabilities in post-communist Central Europe have consistently faced restrictive and entrenched policies of institutionalization (Jenkins et al., 2001), (2) people with mental disabilities are frequently the least well represented group in human rights discussions (Mental Disability Rights International, 1997; Gostin & Gable, 2004) and the least well represented group among disability rights and disability studies initiatives (Scott-Hill, 2002; Chappell, 1998; Parmenter, 2001; Beresford, 2000), and (3) there have been some particularly innovative and successful social entrepreneurial efforts specifically aimed at promoting rights and community-based services for

people with mental disabilities in post-communist countries that might now serve as models for replication and scaling-up.

The institutions of post-communist Central Europe tend to house people with psychiatric and intellectual disabilities in many of the same settings (Rosenthal et al., 1997; Tobis, 2001), which therefore, makes a generic term like “mental disability” a useful descriptor for those who have faced similar experiences within the health and social welfare systems of these countries. Furthermore, the initiatives aimed at promoting disability rights and community-based services profiled below are focused on assisting individuals with psychiatric and/or intellectual disabilities, warranting a general term to describe this group of citizens. It is the shared experience of people with “mental disabilities,” and the need for innovative programs to promote services for them that is most relevant here.

A Brief History of the Visegrad Four Partnership

The four post-communist countries that are the focus of this profile constitute what is known as the Visegrad Four. The Visegrad group of Poland, Hungary, and Czechoslovakia was established in 1991 by the respective leaders of the three post-communist nations in order to mutually facilitate their integration into NATO and the European Union. Two years later, in 1993, Czechoslovakia separated into the two independent nations of the Czech and Slovak Republics, resulting in a total of four sovereign nations in the Visegrad partnership. This geopolitical partnership suddenly became known as the “Visegrad Four.” The term “Visegrad” comes from the name of the town in Hungary where this geopolitical agreement was initially made.

Unlike some of their more resistant post-communist neighbors to the East, such as Russia and Belarus, the post-communist Visegrad Four countries have generally been perceived as eager to “rejoin” Western Europe since the dissolution of the Iron Curtain in 1989 (Gerner, 1999). This eagerness has been attributed to the longstanding alliance these countries have felt with regards to Western European democracies (Rupnik, 2002). The Czech writer Milan Kundera, for example, portrayed Central Europe as culturally tied to Western Europe, and historically, an unwilling victim “kidnapped” by the Soviet East (Kundera, 1984). It is also true, however, that other intellectuals, such as the Polish exile and poet, Czeslaw Milosz, cautioned against too sweeping of a characterization of the whole of Central Europe, and suggested that cultural and religious differences between some of the Central European countries had different implications for their respective contributions to a common Europe (Subrt & Dolezal, 2004). This message has been emphasized by other contemporary Central European figures and scholars (i.e. Nodia, 1996; White, 2003) who also warn against a homogenous view of the region—a view that would understate the troubling persistence of regional and ethnic tensions within and among some of the post-communist Central European nations (Karklins, 2000; Vermeersch, 2002; Frankland, 2004). These regional and ethnic differences, however, do not negate the similarity of very general developmental trajectories that are occurring across these four post-communist countries which prove useful when evaluating them according to mental disability issues and the specific grassroots responses to these issues, as is the aim here.

Possibly most relevant when considering disability rights specifically, the Visegrad Four countries were perceived by many of their native intellectuals (i.e., Vaclav Havel in the Czech Republic, Gyorgy Konrad in Hungary, and Adam Michnik in Poland) as sharing value for a civil society (Gerner, 1999) even, or especially, during a time when civil society freedoms were suppressed under communism. The current shortage of civic volunteerism in the post-communist region notwithstanding (Howard, 2003), this anti-authoritarian ideological support for civil society activism united intellectuals and many citizens in these countries along certain democratic values. It is this history of democracy development and activism that does indeed have relevance now for the disability rights movement, as well as for other human rights movements, occurring within these Visegrad Four countries. The history of simmering dissent during the authoritarian period has given rise to a contemporary civil society movement with substantial momentum, if insubstantial resources.

The Persistence of Total Institutions in the Visegrad Four Countries

The institutionalization of people with mental disabilities is obviously not a practice unique to communism, post-communism, or Central Europe. Institutionalization was the dominant reaction to people with mental disabilities in most parts of the Western world from the 19th century until as recently as the 1960s and 1970s (Fabrega, 1991), when a slow process of change occurred in some regions as the result of a growing, if uneven, emphasis on human and civil rights for people with disabilities. The resultant shift in many Western countries was, in varying degrees, towards community-based rehabilitation and independent living for people with mental disabilities, with a gradual reduction in the numbers of people confined to, what Erving Goffman (1961) famously termed, “total institutions.”¹

But, the de-institutionalization movement experienced in the West did not occur at the same time for communist Europe. There are a number of complex reasons why a particularly massive infrastructure of institutions and asylums was implemented in Central Europe during the communist period, and why this infrastructure persists today in varying forms across the Visegrad Four countries. The most significant reason is that economic progress in the post-communist countries has been given greater priority than social policy in most cases (Sinecka, 2009), resulting in a visible growth in market capitalism that is not matched by evolution in social policies, such as minority rights. Rapid privatization and a diminishing role of the state has resulted in a lack of attention to certain state supported social services that bear little or no potential for private sector financial success (Fajth, 2000; Deacon, 2000). So, while impressive economic and political progress has taken place in the region, many of the transitioning countries of post-communist Europe, including the Visegrad Four countries, currently maintain institutional settings for people with mental disabilities that are unacceptable according to international standards (Human Rights Watch, 1998; Disability Rights Advocates, 2001; Mental Disability Advocacy Centre, 2007). Indeed, Disability Rights Advocates (2001), an NGO based in the U.S. and Hungary, has stated that, “No country in [post-Communist] Central Europe has major institutions for the disabled which can be regarded as fully acceptable under contemporary standards” (p. 6).

The Cultural and Political History of Institutionalization under Communism

The reasons for developing, and then maintaining, the institutional infrastructure for people with mental disabilities in many of the communist countries were politically, economically, and socially motivated. Politically, mental disability presented a bit of a quandary for Stalinist ideology and its derivatives. To the extent that most personal and social “problems,” including mental disability, were presumed rooted in the vicissitudes of capitalism (UNICEF, 1997), the persistence of people with mental disabilities within a communist system presented an awkward challenge to this presumption. Furthermore, the uniform emphasis by the state on clearly circumscribed work roles was problematic for those families who had a child with a disability, since care in the home often compromised availability for participation in collective work settings. Placement of children in institutional care was deemed efficient and humane, if not by the parents and children involved, then by the abstract ideology governing the populace (Iarskia-Smirnova, 1999).

Compounding this political momentum was a general cultural development that infiltrated even the communist bloc. People with mental disabilities were sometimes considered a chronic embarrassment to Victorian era Central European communities, given what was then the emerging theory of “Degeneration,” which posited that people with mental disabilities contributed to social and genetic decay in kin and communities over time, and were a mark of weakness within a family (i.e., Morel, 1857). This theory was later propounded by the eugenics movement in the United States (Black, 2004).

As is well known, the problem of institutionalization was carried to its functional extreme in the Central European countries under the Nazi regime, when thousands of people with mental disabilities in institutions were eliminated through systematic killing (Haug & Rossler, 1999). The typical Central European citizen may have found the Nazi response to disability grotesque and aberrant, but the well intended state-sponsored responses that eventually followed this pogrom were still misguided, since they continued to emphasize segregation and institutionalization as a means of appropriate care. The result in communist Europe was an entrenched and powerful ideological, sociopolitical, and economic push towards the continued institutionalization of people with mental disabilities, often occurring in early childhood and continuing for life (Tobis, 2001).

Even for children with disabilities, who were not committed to total institutions in communist Central Europe, segregated educational environments were imposed, resulting in another form of invisibility, stigma, and compromised opportunities. As noted in a fact-finding report for UNICEF conducted in 1999 by Mental Disability Rights International (MDRI):

“During [the first half of the 20th century], educational philosophy insisted on a State where as many children as possible could be brought up to standards that were predicated on ‘normal’ development. This tradition still prevails today in Russia and much of Central and Eastern Europe. ... Thus, instead of making schools accessible to children with disabilities, the child is excluded from school until he or she can be ‘corrected.’ In practice, some children will never conform to an inflexible ‘norm’ and will remain in separate, segregated schools her or his entire life” (p. 10).

One must be careful not to confuse popular Western anti-communist propaganda of the period with the complex reality of what was occurring in communist Europe, whether regarding the treatment of people with mental disabilities or otherwise. Nevertheless, it can be suggested that the communist-era emphasis on collective organization over individualization, and the ideological position that the state could substitute for the family in certain ways (UNICEF, 1997), contributed to the belief in the advantages of institutionalization, both for the family and the individual with a disability. While this belief has since been challenged by disability activists in post-communist Europe, the attendant institutional infrastructure that originally stemmed from this belief has not changed much despite dramatic economic and political transitions in the Visegrad Four countries (Harangozo, Dome, & Kristof, 2005; Brunwasser, 2009). Mental disability and the perceived need for segregation remain conflated in post-communist educational and medical paradigms (MDRI, 1997; Mental Disability Advocacy Centre, 2007). This perceived need for segregation continues to justify the need for total institutions for those individuals assumed to have severe mental disabilities. The inertia of state agencies and institutional bureaucracies also serve to sustain this institutional system (Orlwska, 1991; Siska, 2006; Brunwasser, 2009). The result is a massive number of children and adults who will continue to be confined to institutions, even for long periods of time, if no contemporary interventions to promote de-institutionalization are aggressively pursued. Such interventions will depend on international policy like the UN Convention on the Rights of Persons with Disabilities, domestic legislation such as employment and housing protection, and civil society organizations such as disability NGOs.

The current era is one in which disability has gained tremendous visibility and import as an international human rights issue. International policy like the UN Convention will help to spur domestic legislation “from above,” while grassroots NGO activism will continue to demand progress and offer alternatives “from below.” Unfortunately, reports of what is occurring at this grassroots level are much less plentiful than those detailing the actions of large and powerful international bodies like the UN. What follows, therefore, are examples of some of the grassroots NGOs that are executing innovative and necessary efforts within the Visegrad countries “from below,” since profiles of efforts being made at this ground level of activism remain few in number, but are indeed sorely needed, if a comprehensive and inclusive portrait of progress in disability issues is to be had.

The Role of Non-Governmental Organizations (NGOs)

NGOs are best conceived of as a subcategory within the elaborate and layered network of relationships and groups termed “civil society.” Civil society can be described, in the broadest sense, as a realm of social and collective interactions that are distinct from both the state and the market (Kaldor, 2003). The concept of civil society has had particular historical significance in Central and Eastern Europe, where it came to represent the pursuit of free association and collective action in the context of authoritarian states (Myant, 2005). Initially, the forms of civil society that were promulgated by Central and Eastern European activists were not NGOs, of course, since such nongovernmental entities were not permitted in most of the communist bloc. However, alternative, informal organizations, many focused on grassroots resistance, existed in a political underground particularly during the twilight years of communism in the Visegrad countries (Havel, 1990; 1991).

From the underground activists led by figures such as Václav Havel, to the Solidarity movement in Poland, self-organized groups led the charge for democratic transition in the Visegrad countries. Since the 1989 dissolution of communism throughout Central and Eastern Europe, self-organized groups in the form of NGOs have continued to be among the most important vehicles for change in Central and Eastern Europe. NGOs specifically addressing disability issues too, have been a crucial form and method of collective action in the post-communist countries, and currently bear a great deal of significance for disability issues throughout the region.

While attention to the experiences and goals of disability NGOs have been recognized as essential to understanding disability issues across various world regions and national contexts (United Nations, 2003; Jenkins, Klein, & Parker, 2005), few sources exist in the disability studies or disability policy literature that offer specific examples of these disability NGOs or a sense of sociopolitical context within which they must function. The review and profiles offered here aimed to address this void by offering a contextual background and some specific examples of disability NGOs in the Visegrad countries. The intent here is that such information could prove useful to international agencies, funding sources, disability groups, or individual activists in other parts of the world with an interest in supporting or collaborating with disability NGOs in the post-communist region.

NGOs Promoting De-Institutionalization and Independent Living

The role of NGOs in the provision of services and advocacy for people with disabilities has long been crucial in democratic contexts. The rapid growth of such entities in the post-communist countries speaks to the urgent need for such organizations, both in terms of service provision (such as vocational training or special schools) and human rights advocacy. Many of the disability NGOs in the Visegrad countries are accomplishing a great deal with very few resources. It becomes essential then, to make the efforts and goals of these NGOs better known, since an increased visibility and understanding of these efforts is necessary in order to advocate for their sustenance. What follows are brief profiles of some notable disability NGOs in each of the Visegrad countries. These NGOs were selected either because they represent a particularly innovative approach to promoting disability rights and independent living, or because they are addressing a critical need largely ignored by the agencies of the state. Most of these NGOs do not stand alone in their mission or goals. There are dozens of other examples that could have been selected to accomplish the portrait offered here. The author, however, is most familiar with the particular examples below as a result of doing work in the region. This selection of profiles therefore, serves as a convenient collection of innovative disability NGOs aimed at demonstrating what such organizations are achieving in the post-communist Visegrad countries.

Slovakia

A small group of disability activists and regional government agencies have forged a number of highly innovative efforts to promote de-institutionalization and independent living in Slovakia (Holland, 2003). These efforts have been successful despite daunting resource shortages experienced by most of these NGOs. What follows are specific examples of innovation as pursued

by one NGO and one partnership arrangement between a regional government agency and disability NGO, a partnership that has created one of Slovakia's most progressive social care homes. Both examples highlight some of the ongoing efforts at reform in disability policy and services that have succeeded in Slovakia.

The Alliance for People with Disabilities

One of the most innovative disability NGOs in Slovakia has been the Alliance for People with Disabilities (The Alliance), led by Dr. Maria Orgonasova. The Alliance functions as an umbrella organization, serving to bring together approximately 35 local and smaller disability groups scattered throughout the country in order to optimize the groups' common interests by increasing their impact through greater collective size. While a number of umbrella organizations exist in Slovakia, The Alliance has been particularly distinctive in its focus on lobbying for policy and legislative change. Many of the disability NGOs in Slovakia, as in other parts of post-communist Europe, continue to focus on service provision rather than policy activism. This service provision is imperative, but it often occurs at the neglect of broader social change through evolving disability policy. The Alliance has worked to address this void. Dr. Orgonasova has sought advisory roles to the Slovak Parliament and, most notably, devised a strategy which involved recruiting highly talented individuals with disabilities and preparing them to run for seats on the Slovak Parliament, thereby integrating the parliament with members who would promote disability issues as a priority (Holland, 2003).

The Kompa Social Care Home

One notable advancement in service provision in Slovakia has been the Kompa social care home in Banska Bystrica, a medium sized city in central Slovakia. The Kompa constitutes a partnership between the regional social welfare agency and an NGO in Banska Bystrica. It is funded by the regional government, so it is a state operated facility, but the regional agency directors have entered into a partnership with an NGO called ANNWIN. The NGO helps to foster a community-based living model for the home, and initiates collaborative relationships between Kompa and organizations independent from the regional government agency. Kompa is a residential program for children with developmental disabilities in which most of the children reside from Monday through Friday. Children participate in the educational program during the day, stay in the program's dormitory during weeknights, and return to their families on weekends. The reasons for this partial residential arrangement is that services for children with severe disabilities are still not available in many of the rural areas of Slovakia, so a centralized, partially residential service model continues to prevail. Unlike many social care homes in Slovakia, however, the Kompa home is not "invisible," located in some remote and isolated area. Instead, it is located on the center square of the city. Children are integrated into the community, if not yet in integrated schools, through activities with the general population of the town. The dormitory is spacious and rooms, while shared, are not over-crowded, unlike many of the institutional settings in Slovakia. The children of Kompa, while not yet fully integrated into Slovak life, nevertheless promote the visibility of disability in Banska Bystrica through their active presence in the community. This, in itself, is progress, both for the children of Kompa and the larger nondisabled population of the town. Until decentralization of services is completed in Slovakia, with community-based programs and inclusive

schools available throughout the country, centers like Kompa could constitute an intermediate option.

Poland

Poland has a long history of innovation and activism at the grassroots level, both under communism and since its fall (Linz & Stepan, 1996). Polish society has also tended to respond to disability somewhat differently than the other Visegrad countries. For example, during the communist period, there was less political, social, and economic pressure in Poland to place children with disabilities in institutional settings, and a greater tendency to care for them in the home (Mrugalska, personal communication, November 7, 2006). Custodial institutions for people with mental disabilities still existed, but this institutional infrastructure was not as pervasive or as inescapable as those in many of the other Central and Eastern European countries. Still, educational, social, and vocational services for people with mental disabilities were severely lacking in Poland, and the response to this void has been dramatic since 1989, with the accelerating growth of service-based disability organizations that existed in very quiet and modest forms under communism, as well as the establishment of new NGOs with innovative and creative missions and methods.

Polish Association for People with Mental Handicap

The Polish Association for People with Mental Handicap (The Association) was founded in 1963 and represents one of the first nationwide parents' movements in the communist block. The Association was initiated in order to address the complete exclusion of children with developmental disabilities from educational, recreational, and vocational development. During communism, The Association focused on developing its own programs to provide assistance to children with developmental disabilities, establishing special schools and recreational programs throughout different regions of the country. In the early years of its development, The Association was also focused on providing community-based support to parents in order to foster more comprehensive care in the home, and later established group homes for adults with developmental disabilities to live in the community (Mrugalska, personal communication, November 7, 2006). In 1976, it was among the first organizations in Poland to implement early intervention programs for children with developmental disabilities. Under communism, The Association operated as one arm of a larger quasi state-run social welfare organization. In 1991, The Association was able to establish itself as an independent NGO.

The Association's history as the first parents' organization in Poland to promote the greater integration of children with developmental disabilities into community life lends it a prominent status now in the contemporary disability NGO community. Many of The Association's current goals are quite similar to those of the organization during communist times: educational opportunities, recreational activities, and parental support in the community. The difference now is that The Association is able to operate with much greater freedom and is able to increase the sophistication of the programs it designs and offers. It has also been able to increasingly focus on individuals with more severe disabilities, given that some of the programs it established in the past for individuals with less severe developmental disabilities have been adopted and funded by the state. The Association still provides segregated schools for children with severe disabilities. But, it is the position of The Association that children with the most severe disabilities cannot be educated

at the regular state-owned schools since these are not prepared to respond to their specific needs. The Association, therefore, operates education and rehabilitation centers that provide comprehensive medical, psychological, and educational services for individuals aged 3 to 24. This segregated schooling is endemic throughout the Visegrad countries, and likely represents an interim situation following which integrated educational settings will eventually be phased in. Nevertheless, in the meantime, The Association is managing to provide some of the most progressive and comprehensive educational environments, albeit segregated, for children with the most severe mental disabilities in Poland.

The Association represents an interesting and valuable example of a disability organization that survived the transition from communist to post-communist society. The NGO appears to have done this by maintaining a certain cooperative, if somewhat tense, relationship with the state government even as that state government underwent a massive transformation. At no time did The Association seem to accuse or challenge the government, whether communist or post-communist, with regards to disability rights or even with regards to lack of services. Instead, The Association set out to fill a critical void by providing services the state did not provide, later transferring some of these services to state agencies and moving on to develop new or more sophisticated ones. The Association functioned as a sort of incubator for disability support services and, once these incubator projects were established and proven, used them to convince the state of their necessity.

Grodzki Theater

The Grodzki Theater is an NGO founded in 1999 and dedicated to the promotion of the arts and arts education for children and adults in the rural southern provinces of Poland. The common themes underlying the Grodzki Theater programs are the use of creative and performing arts to promote vocational, social, and life skills, and gearing the programs to serve a diverse collection of populations deemed “socially excluded,” including those with mental disabilities. These themes are broad enough, and the populations constituting “the socially excluded” are numerous enough, that the program gains the advantage of having broad relevance to multiple funding sources. The triumph of the Grodzki Theater appears to be the NGO’s ability to provide a broad array of programs serving a very diverse population without losing its primary focus, which is the promotion of inclusion through artistic involvement. The NGO, therefore, uses participation in the arts as its core rehabilitative function, pervasive across programs and groups served.

The Grodzki Theater is an NGO focused on service provision (as opposed to human rights promotion), which is the most common mission for disability NGOs in the Visegrad countries. But, the Grodzki Theater is clearly accomplishing its service mission through what are atypical methods. This melding of the arts and community-based rehabilitation represents a notable innovation among disability NGOs in the Visegrad countries, and has the potential to demonstrate to the broader disability NGO community in the region how service provision can be diversified and enriched in innovative ways.

Hungary

Hungary could be said to possess some of the most progressive disability NGOs in the Visegrad countries, though up to now, the existence and implementation of disability rights

legislation has not been significantly more advanced in Hungary than in the other Visegrad countries. Hungary has been the first among the Visegrad countries to sign and ratify the UN Convention on the Rights of Persons with Disabilities, as well as the Optional Protocol, so Hungary may now be taking the lead among the Visegrad countries with regards to the promotion of disability rights. Hungary has the distinct problem, however, of having the majority of its most active disability NGOs located in the capital city of Budapest, while the other Visegrad countries have a less severe geographic concentration of disability organizations in one location. As a result, Budapest represents a center of remarkable disability NGOs that serve much of post-communist Europe, but it also represents a relatively concentrated oasis of activism within its own country.

The Mental Disability Advocacy Center

One of the most visible and successful disability NGOs in Hungary is the Mental Disability Advocacy Center in Budapest, a human rights NGO with a geopolitical focus that encompasses much of the post-communist region. The Mental Disability Advocacy Center (MDAC) is distinctive in its visible and vocal focus on mental disability as a human rights issue in the post-communist region. The NGO uses a combination of law and advocacy to advance the rights of people with actual or perceived mental disabilities in post-communist Europe and Central Asia. The strategies used by MDAC are sophisticated and multilayered. For example, MDAC works with individuals at a local level to document and challenge abuses in the national and international courts. At a policy level, MDAC has been engaged with the International Disability Caucus and the process that eventually resulted in the United Nations Convention on the Rights of Persons with Disabilities. In addition, MDAC has initiated the Guardianship Project in the post-communist region. The Guardianship Project addresses the various processes through which people with mental disabilities are adjudicated to lack competence and are assigned guardianship, resulting in no sovereignty over their own lives.

MDAC has received support from the European Council, the Soros Foundation, and other government and foundation sources. Its emphasis on human rights, rather than service provision, has gained the NGO a good deal of influence and attention, in part because such a focus on mental disability as a human rights concern still remains unusual among most of the NGOs in the post-communist region. This important focus has likely enhanced its ability to gain international funding from such sources as the Sigrid Rausing Trust in the U.K., and may have hampered its ability to gain domestic government grants.

Members of the MDAC staff include Gabor Gombos, himself a survivor of the Hungarian mental health system, a former Ashoka Fellow, and one of the human rights pioneers spotlighted in Kerry Kennedy's (2004) book, *Speak Truth to Power*. MDAC has a significant presence not only among mental disability NGOs in the Visegrad countries, but also on the world stage, and its efforts appear to be gaining increasing recognition by the global disability community (i.e., Krosnar, 2006). As disability NGOs in the Visegrad countries begin to assume more of a human rights mission, and not only a service oriented one, MDAC will most likely emerge as one model to follow.

Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ)

The Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ) is an umbrella organization with the dual mission of community-based service provision *and* policy advocacy for people with intellectual disability in Hungary. This umbrella organization represents 50 member associations and has 25 local branches, representing approximately 22,000 citizens throughout Hungary. ÉFOÉSZ was founded 25 years ago, during the communist period by Piroska Gyene, whose son had a developmental disability. It was because Gyene found herself having to navigate her son's early educational and community needs on her own that she pursued the establishment of an organization to support people with developmental disabilities and their families. What makes ÉFOÉSZ distinctive, however, is that it accomplishes both a service mission and an advocacy mission, blending grassroots community-based support with the promotion of improved policies for people with developmental disabilities in Hungary. This remains an unusual accomplishment in the post-communist region, where the vast majority of disability NGOs are service-based and do not pursue an advocacy role. Notably, however, the advocacy most often engaged in by ÉFOÉSZ is not the confrontational, rights-oriented approach of MDAC noted above. Advocacy efforts by ÉFOÉSZ most often consist of public education campaigns, as well as participation in Hungary's National Disability Affairs Council. This collaborative, more than confrontational, form of advocacy may represent the next wave of development for many of the service-oriented disability NGOs in the region, as they extend their foci to include activism, as well as service. If so, ÉFOÉSZ may present a hybrid model for the currently service-oriented NGOs to emulate over time.

Czech Republic

The majority of persons with mental disabilities in the Czech Republic are estimated to live in approximately 200 institutional settings spread throughout the country (Inclusion Europe, 2002). As with the other Visegrad countries, data regarding the nature of these individuals' disabilities, how many reside in which facilities, or even the precise number of facilities serving people with mental disabilities, are lacking. De-institutionalization has been slow to develop (Sinecka, 2009), in part, because legislative and financial support for community-based disability NGOs has been severely limited. Still, despite these challenges, a large number of innovative disability NGOs have succeeded in the Czech Republic and are managing to change the nature and scope of services that promote independent living and community-based support, including caregiver education, supported employment opportunities, and advocacy for educational reform. As with the other Visegrad countries, it is in part the challenging sociopolitical context within which these disability NGOs have had to struggle that has contributed to their reputations as notably resourceful and resilient.

Autistik

Autistik was founded in Prague in 1994 by a group of parents of children with autism to address the perceived lack of national and professional attention to this developmental disability in the Czech Republic. Autistik represents a traditional, service-oriented NGO in many ways, focusing on the provision of supportive services such as vocational training and educational opportunities to people with autism, as well as therapeutic respites for families. The NGO might be said to adhere to an older model of disability organizations, in that it defines itself according to a specific diagnostic category, but in other ways, Autistik represents a disability NGO that is forging new paths in the post-communist region and resisting the confines of the service-oriented models of the past. For example, Autistik has been vocal regarding the inappropriate incarceration of people

with autism and has challenged policies in the Czech justice system that the organization considers incompatible with the fair treatment of people whose disabilities contribute to unconventional behaviors. Likewise, Autistik has challenged unfair housing practices with regard to adults with autism who are seeking suitable apartments, at a time when many cities and towns in the Czech Republic are experiencing significant housing shortages. Such policy and legislative activism make Autistik one of the NGOs in the post-communist region that manages to balance both a traditional service-provision mission with rights-based activism, achieving a sort of hybrid model among post-communist NGOs that typically adopt only one of these aims.

Centre for Mental Health Care Development

The Centre for Mental Health Care Development (The Centre) in Prague is distinctive in that it has an advocacy mission, but has adopted a largely collaborative method. The NGO was founded by mental health providers who possessed a mental health system reform agenda, thereby serving to promote change “from within.” The Centre has been instrumental in supporting community-based models of support and de-institutionalization in the Czech Republic, establishing pilot programs and conducting needs assessments. The Centre has successfully sought out and collaborated with different segments of the mental health sector, reaching clinicians, institution administrators, and government agency leaders at the ministerial, regional, and municipal levels in order to advocate for more rapid and pervasive transformation of the Czech mental health system. The mission of the organization is to help guide the Czech mental health system from one that over-relies on institutionalization to one primarily focused on community-based services. The Centre has crafted its mission and priorities according to the Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care adopted by a UN General Meeting No. 46/119 in December 1991, and thereby constitutes one of the few mental health NGOs in the Czech Republic to explicitly utilize this international instrument to shape its organizational purpose.

The Centre is one of the few disability NGOs in the post-communist region to assume responsibility for developing assessment and evaluation methods for mental health services. The development of such methods and the conduction of such research are critical if mental health service reform in the post-communist region is to be informed and driven by meaningful data. Indeed, the lack of data regarding mental disability issues in the post-communist region, from little epidemiological information to a few thorough needs assessments, is an urgent concern. The Centre’s efforts to address this void and to begin producing reliable methods for data production are particularly distinctive.

Conclusion

There is clearly a great deal of development and evolution occurring among disability organizations in post-communist Europe. During this period of rapidly expanding civil society freedoms, however, there continues to be a lack of resource support for these disability groups. While the enhanced visibility of disability issues within the international community, such as the United Nations Convention on the Rights of Persons with Disabilities, will foster greater attention to disability rights and de-institutionalization, widespread progress will continue to take time. Both the deconstruction of the institutionalizing apparatus and the creation of community-based supports will involve a shift in values and behaviors among health and education professionals as well as

government agencies. This shift will need to be massive within each of the Visegrad countries, and will require resources, personnel, and policies that are not currently in place. In the meantime, the growth and empowerment of disability NGOs like those profiled here will be essential, since it will be these grassroots efforts that will ultimately be scaled up into much broader initiatives over time.

Certain tension exists within the disability NGO community in the Visegrad countries, and this tension reflects the ideological differences frequently represented by two models of activism (Holland, 2008). One model of activism favors a service-oriented, community-based model in which the NGO provides much needed support directly to people with disabilities and their families. The Polish Association for People with Mental Handicap favors this model, as does the innovative partnership struck between the NGO called ANNWIN and the regional social welfare agency for Central Slovakia, in their creation of the KOMPA social care home in Banska Bystrica. The other, less common, NGO model in the Visegrad countries favors a human rights advocacy approach. This approach challenges government agencies and official powers to do more to protect the sovereignty and freedoms of citizens who have disabilities. The Mental Disability Advocacy Centre in Budapest is an accomplished example of this model. A number of the human rights-oriented NGO leaders suggest that the service-oriented NGOs are providing essential supports, but they are supports that should be the responsibility of the government health and social welfare agencies. By providing such supports through the NGO sector, some of the conflict-based leaders argue, the service-oriented NGOs might inadvertently reduce the pressure on these government agencies to respond responsibly to their own citizens. Leaders from the service-oriented NGOs, on the other hand, frequently term the human rights NGOs as “too political,” and point out that in order to meet the urgent needs of people with disabilities and their families, NGOs must work cooperatively with government agencies and policymakers, not risk alienating them. Jan Pfeiffer, the Czech reform psychiatrist who has been advocating for the rights of people with mental disabilities for many years, is quoted as saying, “You can either be a bad German Shepherd who barks, or somebody who offers a helping hand. Both roles are important, but not compatible. You can’t bark at somebody, then sit down with him at a table” (Stojaspal, 2004). This statement captures much of the sentiment among the NGOs of the post-communist region. Human rights and direct service are often seen as two separate causes, so there is a perception that a choice between one or the other must be made by any NGO. That perceived dichotomous choice then results in the existence of two somewhat separate subcultures within the disability NGO community in the region, and there is some minor tension between these two subcultures.

Yet, it remains important to note that there are a small number of examples of disability NGOs that contradict Pfeiffer’s dichotomous portrayal. Indeed, a handful of the disability NGOs in the Visegrad countries manage to balance both a human rights and direct service mission, adopting the seemingly contradictory roles of “the German Shepard that barks” and “the helping hand.” The Hungarian Association for Persons with Intellectual Disability and Autistik in the Czech Republic seem to have achieved this dual mission to varying degrees. Disability NGOs in post-communist Europe with such hybrid missions may serve a particularly important role in the future if they can come to bridge the two somewhat separate subcultures among the NGOs in the region, demonstrating how the two missions complement one another in effective, if sometimes awkward ways. In fact, the Centre for Mental Health Care Development, an NGO on which Jan Pfeiffer serves on the staff, is itself an excellent and elegant example of an organization that is managing to forge a new form of disability advocacy in the Visegrad countries. It is a form of

advocacy that pushes for change by drawing even historically resistant stakeholders into the process through education, mutually beneficial demonstration projects, and broad based national and international support.

Both of the disability NGO subcultures in the Visegrad countries and each of the two types of missions these subcultures promote, human rights advocacy versus direct service provision, are essential to progress. A report on human rights and mental health in Hungary, compiled by the American NGO, Mental Disability Rights International (1997), notes that, "The history of mental health system reform in the United States and other countries demonstrates that there are dangers associated with legal reform not accompanied by a national commitment to plan and finance community services" (preface p. xx). Such dangers may not seem imminent in the post-communist countries of Central Europe because so much of the emphasis of the disability NGO community is already on service provision rather than disability rights.

Yet, the mistakes made by the United States in its de-institutionalization process in the 1960s and 1970s could still be repeated in these transitioning countries if sweeping disability rights legislation is suddenly implemented without accompanying support for community-based services. This support may need to come from international sources as. As disability rights legislation is inevitably implemented in these countries, particularly now with the catalyst of the UN Convention on the Rights of Persons with Disabilities, measures will need to be taken to avoid the mistakes of the de-institutionalization process implemented in the United States, where a human and civil rights emphasis was not matched with the availability of community-based services, and people with mental disabilities were released from institutions often to fend for themselves. Ironically, as the United States continues to struggle, decades later, with the outcome of its own de-institutionalization effort, it may be well positioned to help other nations avoid the same problems through both international aid and the provision of a living model of how not to proceed. The avoidance of such mistakes, however, will require substantial engagement and investment from other EU and North American countries. Furthermore, a willingness to support the service-oriented NGOs, as well as the rights-oriented ones, will need to be paramount. Such support will ensure that de-institutionalization is met with community-based services and pragmatic support, and does not simply result in post-institutional homelessness and neglect.

The partnership among the Visegrad countries may also prove critical during this emerging era of disability issues in the post-communist region. Some have suggested that the Visegrad Four partnership is virtually irrelevant now that all of the member countries have reached their original goals and have entered NATO and the EU ("From Visegrad," 2005). It may be, however, that one of the next waves of coordinated advancement to unite these four nations will be in the area of minority issues and human rights, which would retain the relevance of the Visegrad partnership under a new cause. Such an evolution in Visegrad partnership would make sense, since all four countries now face similar challenges in improving the rights of minority groups, including people with disabilities. For example, it has yet to be seen if Hungary's recent ratification of the United Nations Convention on the Rights of Persons with Disabilities and the Optional Protocol, will influence its Visegrad partners in any way, all of whom have, at the time this article was written, signed, but not yet ratified, the UN convention. Ideally, the furtherance of the Visegrad collaboration would make human rights efforts, like the large-scale de-institutionalization of people with mental disabilities and promotion of

independent living alternatives, a shared priority in the four countries' coordinated march "back to Europe."

Regardless of the shape and purpose the Visegrad partnership now takes, what remains clear is that the disability NGOs of these nations will be essential to the continuing improvement of conditions, services, and rights throughout the post-communist region. What is essential at this time then, is greater attention to what these disability NGOs are accomplishing, what are their needs, and how international and informed crosscultural partnerships might assist some of them in not only surviving, but eventually scaling-up. The profiles and context presented here is one attempt to lend such attention to the disability NGOs of the post-communist region, with the intention of initiating more discourse in the disability policy literature regarding the crucial role of disability NGOs, not only in post-communist Europe, but in the global disability community at large.

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Endnotes

¹A “total institution” refers to an organization in which all aspects of a person’s life are subordinated to the rules, routines, and structures of the institution. A total institution often requires a loss of sovereignty over one’s own life, with deference to the authority of the organization and internal demands (Goffman, 1961).

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