CENTER FOR POLICY STUDIES

SOLIDUS
Solidarity in European Societies: Empowerment, Social Justice and Citizenship

SARA SVENSSON, ANDREW CARTWRIGHT
AND PETER BALOGH

Solidarity in the treatment of mental illness in Hungary: A case study of the Awakenings Foundation as a vehicle for change

2017/6

WORKING PAPER SERIES

ABOUT THE PROJECT

This study was prepared in the larger framework of the project "Solidarity in European societies: empowerment, social justice and citizenship - SOLIDUS" (http://solidush2020.eu). SOLIDUS is a research project funded by the European Union under the Horizon 2020 Programme (Grant Agreement nº 649489), running June 2015 through May 2018. The project explores conceptually and empirically current and future expressions of European solidarity from an inter-disciplinary approach. The paper contains empirical data from a case study carried out in Hungary in the health policy sector in 2016.

ABOUT THE PAPER SERIES

Working Papers reflect the on-going work of academic staff members and researchers associated with the Center for Policy Studies/CEU. They are intended to facilitate communication between CPS and other researchers on timely issues. They are disseminated to stimulate commentary and policy discussion among an international community of scholars.

ABOUT THE AUTHORS

Sara Svensson is a visiting research fellow at the Center for Policy Studies (CPS) at the Central European University (CEU) in Budapest, Hungary, and visiting professor at the CEU School of Public Policy. She holds a PhD in political science with a specialization in public policy. Her recent research focus has been on subnational involvement in cross-border cooperation, but she has also participated in several collaborative research projects in other public administration and civil society areas.

Andrew Cartwright is Co-Director of the Center for Policy Studies of Central European University in Budapest, Hungary and teaches at the CEU School of Public Policy. He has a PhD in Law, and his research concentrates on social and economic development in rural areas, with a special focus on post-socialist countries. He has also supervised and conducted research across a range of collaborative research projects.

Péter Balogh is Research Fellow at the Institute for Regional Studies, CERS-HAS in Pécs, Hungary. He holds a PhD in Human Geography from Stockholm University. His research interests include the study of political and cultural borders, centre-periphery relations, (critical) geopolitics, and national narratives. He was a visiting research fellow conducting research for the SOLIDUS project April–September 2016.

TERMS OF USE AND COPYRIGHT

SOLIDARITY IN THE TREATMENT OF MENTAL ILLNESS IN HUNGARY: A CASE STUDY OF THE AWAKENINGS FOUNDATION AS A VEHICLE FOR CHANGE

Sara Svensson, Andrew Cartwright and Péter Balogh

CONTENTS

1. INTRODUCTION

This case study of a Hungarian foundation active in the field of mental health considers the extent to which civil society organizations can change the direction of state health policy through tactics of solidarity and mutual understanding. As in many countries in Europe, mental health in Hungary is increasingly proclaimed as a serious public health matter. At the same time, it is a sector that remains chronically underfunded, and in Hungary the number of trained mental health professionals in the population is falling as for instance an older generation of psychiatrists is not being replaced by anywhere near the same numbers. To add to the problems of the sector, low wages and poor working conditions are leading younger Hungarian from a number of professions relevant to mental health care, such as psychiatric graduates and social workers, to migrate abroad.

Community based approaches to the treatment of mental health problems are not as common as it is in other countries in Europe. The practice of small-scale patient focused approaches that stress cognitive treatments, self-help and mutual support groups are in evidence in pockets around the country. By far the largest number of non-traditional therapies and alternative institutions can be found in the capital. Even though there are important variations between these different schools or groups, most would characterize themselves as existing in an ambivalent relationship with the more mainstream, hospital centered psychiatry. Sometimes the critique of the community mental health groups focuses on the efficacy of treatments that are relying heavily on prescription medicines. Another difference would be to challenge the strict hierarchical nature of relationship between doctor and patient. A third difference would be to stress the importance of the social roots of mental illness, trying to reduce negative symptoms by addressing problems of bad housing, lack of employment, family break up, loneliness or addictions. Here, the community health advocates would see their primary allies as social workers, counselors, and local authority officials.

From this point of view, our study focuses on a single civic group – the Awakenings Foundation (Ébredések Alapítvány) – which combines practical support for those suffering from a range of mental health conditions with an explicit agenda to change public and professional views of mental illness. Our focus is to explore the association's efforts to show solidarity with the mentally ill and to convince others in the psychiatric and other relevant professions, key policymakers and the wider public of the virtue and efficacy of this approach.

The empirical material for the case study consists of eleven interviews, organizational and policy documents and participant observation in two public events organized by the Foundation. Interviewees were selected as to have both inside and external knowledge of the institution, and to represent both professionally engaged and clients. Access was gained via the Director of the Foundation, which to some extent influenced with whom we could meet. The interviews were carried out in English or Hungarian between March and November 2016. Relevant parts of the interviews were translated and transcribed in English. See the list of interviewees at the end of this working paper. Interviewees have

been anonymized, with the exception of the Director of the Foundation, who as the public face of the organization and decade-long involvement, could not be credibly anonymized and did not request to be so. In addition, the Foundation was represented in a focus group on solidarity practices in Hungary, which took place in July 2017, which validated some of the conclusions in this report. In general, however, all statements refer to the situation as of end of 2016.

The paper starts with an empirical account of the development of the Awakenings Foundation since its inception in the early 1990s and review their main activities today (section 2). We follow with an analysis of the organization in relation to the policy landscape which surrounds it (section 3) in which we also elaborate on the statistical references given in this introduction. We then proceed to analyze the different professional groups that the Awakenings Foundation interact with (section 4), before discussing policy change in terms of impact, recognition and scalability (section 5). We conclude with some remarks on how assumptions of what constitute mental health is can influence the potential for solidarity, and on the importance of broader global and European developments for how the work of Awakenings Foundation has unfolded. Annex 1 contains more elaborate material, which for reasons of space and coherence could not be incorporated in the body text, from interviews with persons who are simultaneously volunteers and patients at the Awakenings Foundation.

2. THE AWAKENINGS FOUNDATION: EMERGENCE, DEVELOPMENT AND CURRENT ACTIVITIES

At Kálvária tér, in the relatively poor and stigmatized District 8 of Budapest, a run-down building houses the Semmelweis University Community Psychiatry Center. The center offers outpatient and ambulant care paid for by public health insurance, and also offers private psychiatry, psychotherapy, psychology, and addiction treatment related-services at rates that are less than half the market rate.[1] In 2016, it had 58 persons enrolled in continuous community-based care, 390 persons in addiction treatment and 275 persons visited at least once as private patients.

The managing entity of the Center is called Ébredések Alapítvány, in English 'Awakenings Foundation'[2]. It was founded in 1991 with the goal of promoting community-based mental health practice, reduce social stigma surrounding mental illness, and provide practical support for patients and their families, through day care support, employment training, and other social and rehabilitation therapies.

The Kálvária tér building and the community around it has a history of non-mainstream psychiatric care that is older than the Awakenings Foundation. In the socialist Hungary of the 1970s the Community Psychiatry Center that operated in these facilities constituted an exceptional place. Visual artists, writers and even researchers teamed up with the Center due to it being sheltered from investigations by police and authorities. Under the label of 'art therapy' they were free to create without risking consequences

---

1   2016 prices according to the website and confirmed in SOLIDUS interviews: 5,000 HUF (~16 EUR) for a first visit and 3,000 HUF (~10 EUR) for a follow-up visit to a psychiatrist.

2   Named after the 1990 film 1990 Awakenings, possibly as a tribute to the founder of the Foundation, a company started by Hungarian-born American film director Andrew Vajna. This set-up also had monetary advantages at the set-up stage of the activities. The founding company is not involved in daily operations.

(Awakenings Foundation Director, HEA 2). The Director of Awakenings, Dr. Judit Harangozó, observed this while visiting as a medical student, and she never forgot it during the years that followed. Later, in 1994, she was offered the opportunity to be the Director of the young Foundation. She agreed, but was dismayed that much of the old alternative and, in her view, progressive 'spirit' had been lost. Shocked by the changed conditions, she decided to rebuild the organization from scratch:

> And when I came I saw pretty chronic patients, standing on this yard, it was in the autumn, very dark weather, very dirty, it was really very depressive for me to come here. I saw that the patients here are frozen people, smoking, I saw that I don't like to do such things, which gives this result, you know, so I had a personal crisis. Then I started to learn what is rehabilitation, because I didn't know it too much, and I went also abroad, where we could really, the first year we could get in contact with the best people in the world, to cooperate with. (Awakenings Director, HEA 2)

Using what she had seen and learned as a psychiatrist in Hungary and adding to that insights from frequent trips abroad in the second half of the 1990s, she started to build up the Foundation as an entity that would challenge the poor conditions and treatment of those suffering mental health problems. The goal was to promote a more community-based mental health practice, with the active involvement of the patients in their own recovery as well as in the recovery of others. An interviewee who was interviewed for this study together with his social case worker told how he had gone from without occupation to having a job five hours per day, which means that he now comes less to the Center.

> Now slightly less often, as I get tired from work [laughs]. I'm still coming here to paint, although I recently left the painting workshop as I had a smaller conflict with one person, but a friend convinced me to stay. <Interviewer: This environment looks different from a hospital."> Right, fortunately not at all. Employees here are very nice, too, and flexible. (Patient and volunteer, HEA 4)

As noted in the quote above, the task to lead the painting group is not without challenges, although it is also rewarding.

> They [either the painters or the group coordinators] said they like that I don't direct them and get involved with their paintings and thus asked me to be the third coordinator. I still wonder why they put me in this position, but it does feel very good. The coordinator put me on an equal level – although I remain humble about it. One has to deal with conflicts daily arising among participants. <…> Some people are so sick they don't know if they should draw or paint. I then equip them with tools for both. One patient could only paint cats before, but now many other things, too. (Patient and volunteer, HEA 4)

The organization also stressed the importance of changing attitudes and reducing social stigma surrounding mental illness. The aim was to counter the idea that there was something shameful about depression, schizophrenia, and psychoses which meant that treatment should be hidden from plain sight. Finally, the goal was to provide practical support for patients and their families.

The practical dimension of care would be realized by setting up day care support, employment training, and other social and rehabilitation therapies carried out with an integrated approach. This entails working with the people and the environment surrounding the person, including the patient and his/her family, friends and neighbors, but also the other state institutions with which they have been in contact. In recognition of the continuing stigma that some people attach to visiting a psychiatric facility, the foundation allows and in some cases actively encourages consultations outside the premises of the Center as well as home visits are also part of this approach, as is the support for various self-help groups e.g. 'The Hearing Voices Group', 'the Bi-polar' group' and 'the Art Group'. In addition, this active advocacy work both for specific patients and for the rights of all with mental health issues is an integrative component.[3] Importantly, Awakenings Foundation stresses that the difference between mental 'health' and mental 'illness' is smaller than many believe, and in some instances non-existent (Csontos 2015).

Six persons external to the Awakenings Foundations were interviewed for this project to see the views from the administration and the medical profession, and several testified to having witnessed that this approach is evident also for a casual observer.

> *I went to Christmas celebration twice, we have good personal and professional relations. I also think that they built up a model of integrated services, with the objective of reintegration, even quite touching examples of rehabilitation of the whole family, where there were traumas involving many family members. They had the energy and time to sit down with the family members. <…> The word 'community' is really the key; you not only go after the individual, but also the whole family and broader personal relationships, with the objective to rehabilitate both the patient and the family. as quickly as possible."* (Department of Public Health official, HEA 8)

> *This woman <Judit Harangozó> I know that she gives her own mobile number, to perhaps 1,000 patients. If they are in trouble, they can call her. That shows an incredible commitment. Everyone should do that, but I cannot ask everyone, but everyone has the right to a private sphere, but it shows how much they're focusing on the problem. (Senior medal physician HEA 10)*

Adhering to its preference for integrated responses, the Foundation employs social workers, psychologists, therapists and psychiatrists, and in 2015 had 15 volunteers coming from different backgrounds. Developing good cross-sectoral professional ties with health and social services is important for the kind of reforms the Awakenings Foundation would like to see, and over time they have developed a very good relationship with the social work sector. Through the social sector, a network of community-based psychiatric services has been set up in different parts of the country, which is something the Awakenings Foundation supported.

Since 2005, the Foundation has been a legally independent part of Semmelweis University. The University owns the building, but it was agreed that the Awakenings Foundation can use it in exchange for provision of community psychiatry training for medical students from the university. The University also has bought out-patient care from the Foundation. For various reasons, the relationship between the

---

3   It has been suggested that this advocacy work partly needs doing in the absence of effective patient rights groups (Senior psychiatrist, HEA 11).

University and the Foundation has been fraught with complications that are not resolved up to this day. According to the director, the University often treats the Foundation as a marginal sub-branch of its activities. The contract was modified in 2015, and now contains a plan to reintegrate the Foundation's activities, but to keep it as a 'semi-independent' group within the University.

The daily management of the Center at Kálvária Square is the Foundation's most important activity, but it is important to note that it also runs a Mental Health Forum (www.lefnet.hu) to spread the approach of community-based care among health and social sector professionals through studies, reports, conferences and workshops. In addition, in 2009, it initiated an anti-stigma civil network called Nyitnikék[4] that seeks, primarily through monitoring media reporting of mental health issues, to counter bias, misreporting and thereby reduce negative attitudes among the general public. The work of the organization is divided along three different but interrelated goals: to change attitudes (1) in the profession; (2) in the general public; (3) and among carers.

Like many NGOs in Central and Eastern Europe, the Foundation is rather dependent on public finances. In 2014 its budget was 74 million HUF (approx. 220,000 EUR). Out of that, 15 million HUF (approx. 47,000 EUR) came directly from state support, either from the local budget or from the national healthcare service. Of the remaining direct support from the public was about 7 million HUF, project-based activities another 7 million HUF, and foundation related activities brought in 43 million HUF. The latter includes the contract-based provision of healthcare on behalf of Semmelweis University, which means that the majority of funds comes from public finances.

This can make the Awakenings Foundation vulnerable, which was shown in recent years; since 2010 it has received less public funding. About 12 million HUF a year has been reduced, causing various problems for daily operations, which partly has been solved by providing some services for a fee to the patients. The fee is significantly lower than market-based prices, but covers some of the costs of running the Center.

Finances are transparent, although the Director admitted having had problems with fulfilling administrative requirements in the past. This especially appeared when the Foundation started working more with the social service sector, and not only with the health sector.

> They introduced a strong quality control system, which was very bureaucratic in the first ten years. We were the introducer of these services in Hungary, but we also got punishment, some million HUF, because the papers were not good <laughs>. But I understood later that they were right, because in the health system there is no control, so I was not used to really make proper lots of paper and put in nice place and well-organized system of administration, this because in health it was not like that, in the social field this is very dominant. (Awakenings Foundation Director, HEA 2)

Due to the difficulties experienced in the administration of projects, a challenge for the organization has therefore been to develop project management skills, and while the Director indicates that significant improvement has been achieved, it has not been possible to find independent verification of this.

4   (http://www.nyitnikek.hu/index.php?p=kezdolap),

3. THE AWAKENINGS FOUNDATION WITHIN THE MENTAL HEALTH POLICY LANDSCAPE

As seen above, the seeds for what would be the Awakenings Foundation was sown during Hungary's socialist period (ca. 1948-1989/1990). During this time, mental illness was largely dealt with via a hospital-based care system (Dlouhy 2014) that saw mental illness as a neurological disorder to be treated primarily with medical or electro therapy. During the early years of socialism, psychology and psychiatry was actively countered by the state, and psychiatry had to struggle to establish itself as a profession in its own right towards the end of the socialist period (Buda et al. 2009).

Following the transformation from state socialism to democracy, policy-makers expressed their ambition to transform the system to one based on outpatient facilities (Dlouhy 2014) and also put increased emphasis on bringing together different groups from society, such as churches and NGOs, to discuss the role of 'mental hygiene' (as it is was termed) in society (Buda et al. 2009).[5] At the same time international actors promoted 'deinstitutionalization' in Hungary as part of the reform of the Eastern European block. Whilst there were undoubted problems in the psychiatric institutions, it soon became clear that the promotion of deinstitutionalization did not come automatically with increased resources for community based, outpatient care (WHO 2003:18).

Thus, the Awakenings Foundation was initiated at a time that favored change, but (lack of) resources and institutional conditions were still disposed against such change. While the Foundation built up its activities in the 1990s, a network of outpatient clinics was set up across the country, referred to as 'care units' (*gondozók*) and hospitals strengthened their outpatient units. During the 2000s the basic numbers in terms of units, number of staff, and number of patients was relatively stable, but with a slight tendency to increased number of patients but fewer doctors.

This basic organization of psychiatric care in Hungary has remained. Those suffering from severe or chronic conditions are looked after through in-patient units that are usually part of hospitals found in most large urban areas. In Hungary, there are about 3,000 acute beds (Hungarian Statistical Office 2014) and 5,500 rehabilitation beds with an average stay of 44 days, or 7.5 psychiatric beds per 10,000 inhabitants (WHO 2014), Then there are out-patient facilities throughout the country that provide respite care and treatment for nearly half a million persons (WHO 2014). Some of them are tied to hospitals (187 providers and 400,000 patients), and others are special out-patient care centers (Gondozók, 122,000 patients)

---

5   By coincidence, this took place at the same time as the introduction of serotonin-based drugs (Prozak and similar) that led to increased medication and reductions in suicide in many countries, including Hungary,

**Table 1. Psychiatric beds per 10,000 (2011)**
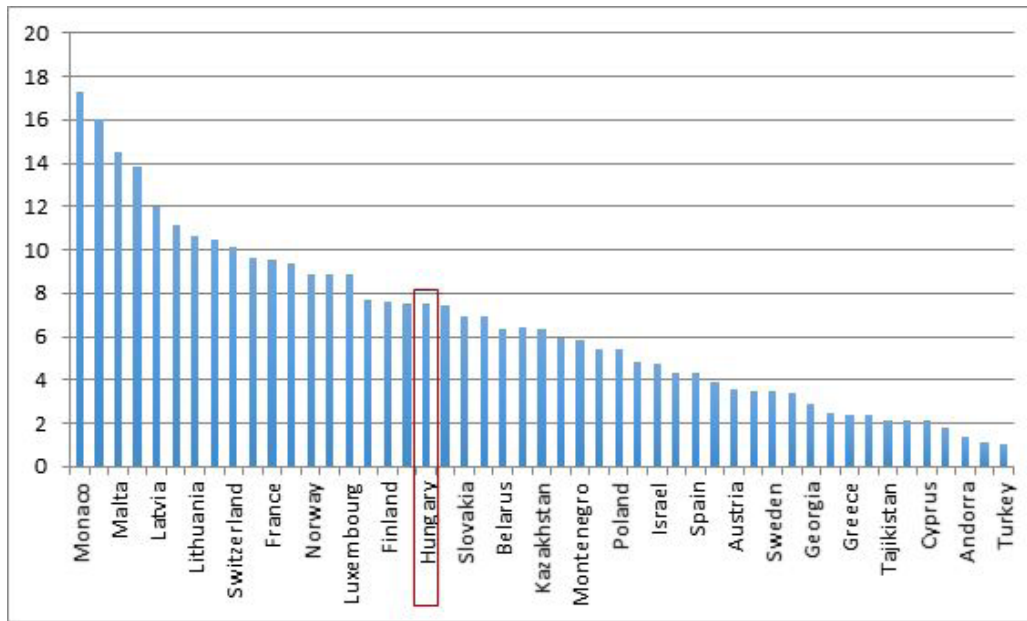
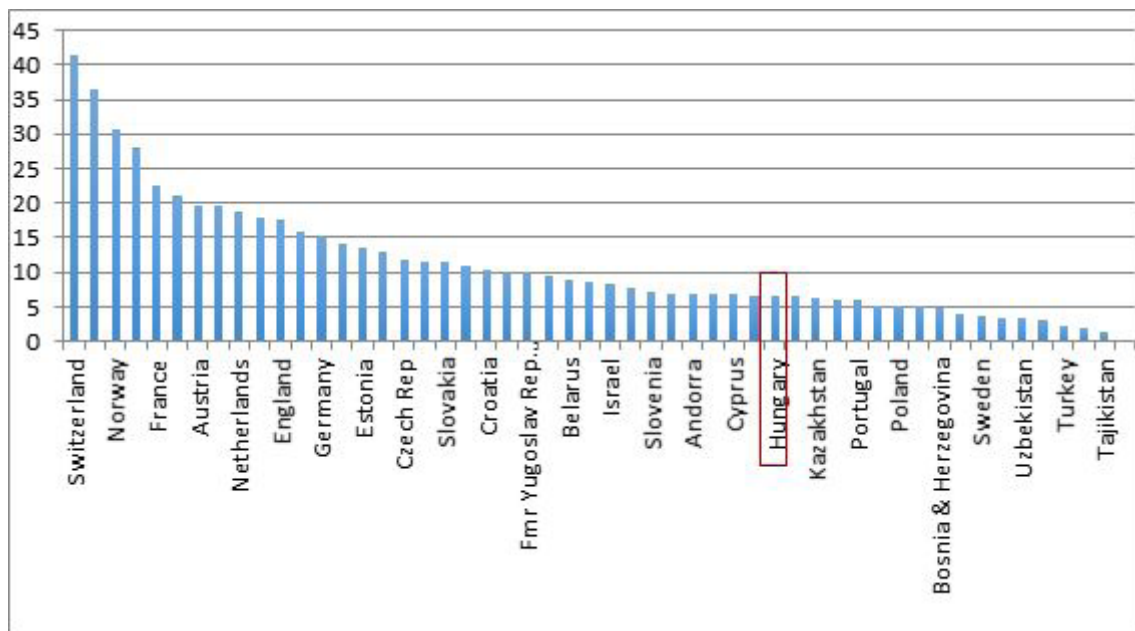Source: World Health Organization 2014

Again, there are problems of funding for some of these care centers, with small numbers of state employed professionals handling large numbers of cases, often intertwined with social and addiction related problems.

The number of trained mental health professionals in Hungary is falling as an older generation of psychiatrists are not being replaced by anywhere near the same numbers and increasing numbers of doctors migrate to wealthier European countries in order to secure higher pay. Added to this the wider problem of the underfunding of the health sector, and psychiatry is strongly affected by the problem of brain drain. See Table 2 and Table 3.

Table 2. Nurses in mental health per 100,000 population
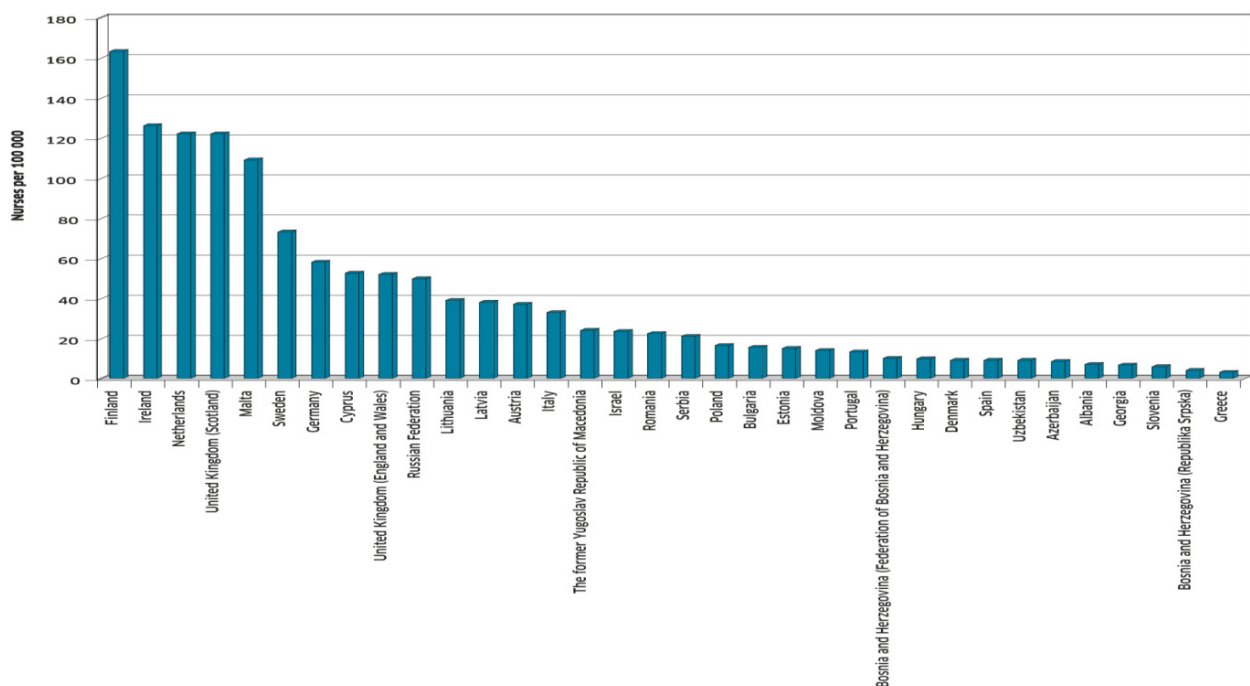
Source: World Health Organization 2014

**Table 3. Psychiatrists per 100,000 population (2011)**

Source: World Health Organization 2014

There has not been a similar debate around brain-drain of other relevant professions there is no system that collects personnel information on all those working in this field in Hungary. A search on the web shows plenty of opportunities for social workers and therapists to work in other European countries, and anecdotal evidence shows that these offers are increasingly being taken up.

It should also be mentioned that the numbers given above refer to specialist psychiatrist care. However, there seems to be agreement in the profession that the general practitioners (house doctors) dealing with most patients can play an important role of gatekeeper and referral. Studies on suicide for instance have shown that in the majority of cases, the last health profession representative someone might see before the attempt is her or her GP, hence the interest both in professional training in identifying signs of impending crisis (Rihmer et al. 2013).

While mental illness can take many forms and shapes, and the line between health and illness is often not that clear, one of the most dramatic outcomes of mental illness can be suicide. Hungary has long had among the highest rates of suicides in Europe and the world. In fact, between 1960 and 1990 Hungary topped the world list for most years, and number remain high. However, since 1990 numbers have declined. Suicide is a multi-causal event, and some factors have been proven to cause this decline why others do not (for instance, high intake of alcohol is supposedly positively related to suicide increase, but cannot explain this, higher prescription of anti-depressants on the other hand, seems to play a role). (Rihmer et al. 2013)

Figure 1. Suicide rates in Hungary 1961-2011
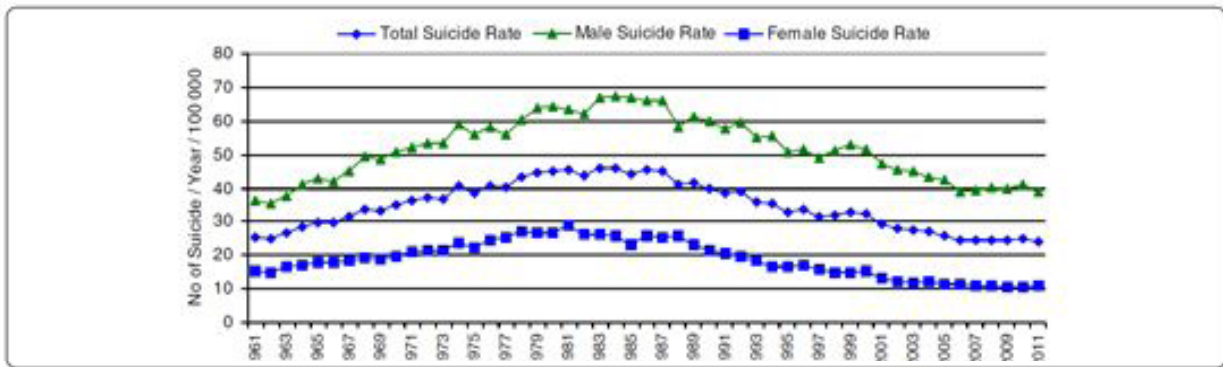
Source: Rihmer et al. Annals of General Psychiatry 2013, 12:21

Suicide prevention does not feature prominently as an independent goal or activity per se for the Awakenings Foundation, and we received indication that some in the medical profession doubt their efficacy in this area. At the same time, in its course of promoting a healthy community-integrated life suicide prevention is one area in which they Awakenings is active. The anti-stigma group Nyitnikék has actively campaigned for media to be responsible in how they cover suicide, and the Awakenings Foundation is usually mentioned as one resource where to turn for people in need (e.g. the website www.ongyilkossagmegelozes.hu, meaning 'suicide prevention', a website run by an NGO affiliated with a hospital).

Even though out-patient care, especially the care centers, in theory should be adhering to many of the same values as Awakenings, it is clear that in practice there are clear differences between the different groups. The WHO Assessment team in 2014 wrote that state run care centers are "more ambitious, targeting patients with severe and long term mental health problems, "but that they are very diverse and unevenly scattered across the country. The report highlighted that NGO-run community centers are more likely to follow best practices rather than the state *gondozók*. "Some of the best centers have been initiated by NGOs, with strong and committed leadership, but often relying on short term funding. Sustainability of such centers should be facilitated." (WHO 2014: 14) The report also highlighted that "in practice the role of different service providers - particularly the *Gondozó* - are not always very clear, and do not seem to be limited to the care of chronic patients. A focus on people with or at risk of severe and enduring mental disorders, aiming to prevent hospital admissions and support community integration, would be appropriate." (WHO 2014: 14)

On a broader strategic level, a National Programme for Mental Health has been 'under elaboration' since the mid-2000s, but had not been finalized as of August 2016. Representatives of Awakenings Foundation have been invited to a number of talks related to this strategy, but is generally seen as too far removed from decision-making levels to be reproached for the failure to adopt it. Hungary has not had any national strategy for the reduction of suicide, and the plan is to incorporate such a strategy into the general plan.

Dlouhy (2014) attributes the difficulties in this process mainly to difficulties for policy-makers to align and satisfy three criteria, each of them comprising a number of challenges: "(a) the policy has to have some sort of connection to the WHO mental health initiatives; (b) the policy has to be accepted in the Hungarian mental health community (dominated by hospital psychiatrists); (c) the policy has to be feasible under current economic conditions" (Dlouhy 2014: 4).

Interviews with two key policymakers (HEA 8 and HEA 9) supports Dlouhy's argument. With regards to the first criteria (connection to WHO), the Hungarian Prime Minister met with the Director General of the WHO to request an external assessment of the Hungarian mental healthcare system. Perhaps unsurprisingly, the core recommendation was to continue with de- institutionalization and place a greater emphasis on outpatient/community care. The Department of Public Health at the Ministry of Human Capacities and WHO Hungary are working on follow-ups to the report in 2016, but up until now, it did not lead to an adoption of an overall program (HEA 8 and HEA 9). Regarding economic constraints (the third criteria), the competition for public sector resources is fierce, but it is worth repeating that despite having poor health indicators in many fields, Hungary still spends below the OECD average both in absolute terms and as a share of GDP. As for the acceptance of recommendations by the Hungarian mental health community (the second criteria), this will be elaborated on in the next section.

It should be emphasized that much development done in this area has been done with the help of external funds, such as the Norwegian EEA grants.

4. THE AWAKENINGS FOUNDATION AND THE PROFESSIONS

According to the leaders of the Awakenings Foundation, Hungarian society is characterized by a widespread deference to expertise and a corresponding neglect of the importance of personal experiences and knowledge. When it comes to mental health, this means that a patient's own lived experience is disregarded as a source of potential remedy in favor of professional expertise. A patient and volunteer at Awakenings says that the main benefit of her first meetings with the Foundation was the realization that she could influence her own illness through recognizing the phases she was in and monitor herself.

> *I was already 39 years old, 20 years of experience of this sickness, and I never heard this expression 'early-sign-symptoms' so that I can monitor myself, and I can work with together with my symptoms. I can prevent ... uh, early warning sign and relapses prevention, so that was a whole new scenario when I ended up here. (Patient and volunteer, HEA 3)*

The foundation seeks to challenge the expertise-deferential approach, which it sees as one of the key obstacles that prevents the development of a more solidarity-based community psychiatry.

> *In Hungary every professional is paternalistic, so the kind of freedom that lets the people decide themselves – this is quite a new culture. For example, when social workers and psychologists come out from university, they see themselves as experts. They are making decisions instead of others, and bring this culture, something that we in turn try to change to the opposite side, and this is the most difficult situation to change. So the interventions, this is not difficult to teach, we have good material for nurses, social workers, even for families and patients. The problem is the approach, which is more than fifty percent of the effectiveness. (Awakenings Foundation Director, HEA 2)*

What is implied here is that Awakenings Foundation seeks to cultivate a receptive audience across a number of professional boundaries in order to make a real difference. These groups include, but are not limited to:

- Psychiatrists and psychiatric nurses working in in-patient hospitals: employed by the state
- Psychiatrists and psychiatric nurses working in outpatient hospital units: employed by the state
- Psychiatrists and psychiatric nurses working in outpatient care units ('gondozók'): employed by the state
- Psychiatrists working as university teachers of future doctors.
- Psychologists: employed in various organizations
- Therapists: employed in various organizations
- Social workers: employed by local government
- Religious communities: in practice this refers to church communities with the three domination dominations Catholicism
- Medical doctors (general practitioners)

Due to its recognition of the value of users and families, it also comes into contact with the professions that these occupy, and strives to utilize their capacities. Recognizing the need for the involvement of multiple actors and multidisciplinary teams is not unique for Awakenings Foundation; many of the outpatient centers in Hungary more or less successfully work with similar approaches. At the international level, it is a trend going back decades. However, solidarity based approaches drawing on notions of equality and reciprocal relations in which for instance those with mental health problems try to help other facing similar issues perhaps proven more difficult to build up in the context of the Hungarian landscape than in many other places.

There are many cross-linkages between these different groups. An annual conference organized by the Awakenings Foundation has achieved a special popularity among social workers, and the capacity to work with this group and spread the foundational values of Awakenings has increased over the years. When it comes to other professional groups, there are many forums for meeting these, not the least in the activities organized by the professional association for psychiatrists.

On the one hand, the Director of Awakenings is invited to all these and have been a focal voice in discussions. She frequently invites users of the Foundation's services to come along, and emphasizes the importance of their voices being heard. On the other hand, there is undoubted skepticism towards her and the Foundations status as outsiders. It is sometimes argued that this semi-autonomous status means that they are unable to fully understand the restraints and limitations inherent in the state system. There is also fear, expressed by an interviewed senior psychiatrist as follows, "a fear <...> about pushing community care too much, because people envisage the closing down of psychiatric institutions, now that would be catastrophic.

In the relation to religious communities the Director stresses the importance to be open for other perspectives:

> *We try to be open to any other ideology, also part of our approach, that people can be familiar with esotery, with church, religion, we are open to that. So we don't say 'this is psychiatry', this is put in the book, 'you have schizophrenia' and the patient says 'no, I have contact with God', then I say, let's speak about that, I want to learn how you think that. I try to make them understand how we think about this, then it developed very nicely, they opened their heart. (Awakenings Foundation Director, HEA 2)*

The Director also describes several productive meetings with Church leaders, which have resulted in them meeting among themselves. In October 2016, the SOLIDUS team observed a round-table organized by Awakenings, in which several church leaders discussed past and ongoing projects and experiences with mental health issues. One speaker emphasized:

> *Of course, we as Christians feel that our faith can give an extra energy to our work. Also, our methods partly diverge (i.e. religious and civilian), but we can both achieve good results. So we have many links and I think we should keep them. (Speaker at Awakenings Roundtable "Religious activities in the area of mental health: best practices", October 18, 2016).*

Due to the relatively strict compartmentalization of medical professions in Hungary, psychiatry in general, and not only Awakenings Foundation, has struggled to influence the gateway health institutions, namely the general practitioners (house doctors). For instance, discussions have been ongoing for year to agree on standardized screening for depression and suicide risk, but without much headway.

However, as a professional network, the Awakenings Foundation has been able to generate genuine interest amongst both psychiatrists and social workers and on that point, we would argue that it plays an important bridging role between the different professional entities, something that has concrete consequences in terms of the community mental health centers around the country.

It is often stated that solidarity derives from identification with a certain group, and we would argue that professions in the research on solidarity has constituted a neglected base for such group identification. Table 4 constitutes an effort to showcase how different professional groups constitute platforms for change (drivers) or status quo (absent or obstacle), and contrasts is with more common theoretical bases for solidarity. It is important to highlight that the table provides a schematic presentation of *perception from the perspective of the Awakenings Foundation, including users of its services*, it should not be seen as evidence of actual practice.

Table 4. Overview of the presence or absence of identity-based motivations for solidarity creation and/or as enablers of solidarity action as perceived by the Awakenings Foundation

Identification base	Driver	Does not feature in discussion	Obstacle	Comment
Professional groups				
Psychiatrists and psychiatric nurses working in in-patient hospitals			✓	General level. Much support shown by individuals. Also shown improvement over time.
Psychiatrists and psychiatric nurses working in outpatient hospital units			✓	General level. Much support shown by individuals. Also shown improvement over time.
Psychiatrists and psychiatric nurses working in outpatient care units			✓	General level. Much support shown by individuals. Also shown improvement over time.
Social workers	✓			
Religious representatives	✓			
Medical doctors (general practitioners)			✓	
Psychologist	✓			
Other bases for identity-generated solidarity				
Affected (patients)	✓			The Awakenings Foundation support several self-help group through the provision of facilities and other material help.
Disability		✓		We could not see any traces of solidarity actions within the broader group of people with disabilities. See also below under 'intra-group'
Family	✓			
Friends, neighbors, colleagues	✓			
Ethnicity		✓		
Age		✓		
Gender		✓		

Source: Authors' analysis based on interview and document data

While state-employed psychiatry is not wholly hostile, as can be seen in the numbers of trainees willing to learn with the Awakenings Foundation, as well as the respect for their work that often generates, the group seems to devote relatively little attention to the outpatient care units, which perhaps would be closest in approach to that of Awakenings Foundation. One reason might be a skepticism regarding how much an NGO can do on its own, without its approach being integrated into the state system.

> *"One of the problems is that the Awakenings foundation never was a gondozó, never was a part of the system. It was a day clinic of this Semmelweis, and then it is sort of separated, they are not so well embedded in the outpatient / gondozó long term system. <…> You cannot*

make foundations in every spot and every city of the country, and to tell people to 'make a foundation'. Because gondozók work the way they work, if you would want that develop, you would need a national program, a policy (Senior hospital-based psychiatrist, HEA11)

Resources play an important role. Poorer European Union countries such as Hungary often lament that they are expected to fulfill lofty expectations on welfare provisions with much lower resources. When it comes to healthcare, public expenditure is less than half of most Western countries (Eurostat 2016). As can be deduced from the interview and observation material, low levels of resources do not drive people towards radical innovation, rather towards making every-day routines work, and guarding that what exists.

Another hypothesis would be professional caution against taking international concepts wholesale and adapting them. A recent large-scale empirical (survey-based) study on the relation between different types of housing in Hungary could not show any positive improvement in quality of life between those living in institutions and in homes in several groups (including people with autism). For people with light mental capacity disabilities the relationship turned out opposite to that shown in Anglo-American studies – there was a statically significant difference in where people in institutions were happier with their lives than those in private homes. However, for patients with schizophrenia life quality was worse in institutions than in group-based homes or private homes (TARKI 2016:15-16). As with the previous hypothesis, to what extent this feature in a web or hierarchy of motivations, would need further empirical data and testing.

5. THE AWAKENINGS FOUNDATION: IMPACT, RECOGNITION AND SCALABILITY

This case study set out to investigate the extent to which single organizations can influence the direction of state health policy, in this case, the treatment of those suffering from mental illnesses, and also what the opportunities are for transferring or upscaling their activities. To do this, we can look more broadly at the impact Awakenings Foundation can be said to have, the recognition it has received and the potential for scalability.

The activities of the Foundation have its most direct and measurable impact on the clients it advises and the people with whom it engages. The Annual Report shows how in 2014, for example, 469 persons, mainly from social and health professions, took part in training in community-based psychiatry care. 59 persons received community services provided within the framework of the contract with Semmelweis University, although this was a substantial reduction in comparison with a few years earlier. However, to make up for the reduction in the scope of the funded service, the Foundation instead drew upon the volunteers from its network and provided low-cost advice (2,000–5,000 HUF per session) for 315 persons.

Since the Center employs a range of professionals, the impact on an individual's life can be enormous, such as she or he is helped to find a job or a flat, which one of our interviewees testified had happened to him. His social worker explained her involvement.

When this crisis hit in X' life, we also had to find him a place to live, which was very difficult. We helped him to find this place, where he lives now. We initially went there to help him get accommodated there. But we haven't been there since last year, as things have become settled now. But we still can come and meet him there should he need us, then we get in touch with the local municipality. Earlier he visited the 'Family helping center' in the 8th district, and there is a similar one in district 19 [where he lives now] but X doesn't go there now as he doesn't have time [due to having a job]. (Awakenings Foundation Social Worker, HEA 5)

More difficult to assess is the effectiveness of the Awakenings Foundation to change attitudes in the profession, to change attitudes in the general public and to change attitudes among carers. As we have seen, there have been measurable changes in the willingness of journalists to report mental health issues in a way which can promote understanding.

The assessment of those involved is mixed on this issue. Hungary has moved towards stepping up community-based care approaches over the past 15 years, though mainly due to advances in the social sector and not the health policy sector. According to Dr. Harangozó, the work of the Foundation has been part of this, but other actors have also been crucial. Overall, she assesses the development as positive: "of course there are problems, but it is a high performance, they started from zero point" (Awakenings Foundation Director, HEA 2). Other interviewees are equally cautious. Eleven persons were interviewed by the SOLIDUS team for this project, and none of them could point to Awakenings having had effect at system level.

"The way I would put it, so Dr. Harangozó and her team, she takes care of several hundred patients here in the eights district, which is important for those particular patients, I would not think that at the national level, the impact is not very big (…) Awakenings is much more bottom-up, grassroots approach, people working in this area see that they want to do something extra, that is the strength and the limitation. (Senior psychiatrist, HEA11)"

They treated an acquaintance of mine, and he/she[6] healed. I went there a lot as well, and I saw that they have very good results. Who goes there … they can bring persons back from hopeless situations. So in that respect I had a positive impression. Ill persons/patients have a role there, they give performances, and they don't see <mental illness> as something bad that has to be hidden. In a way they erase the difference between the ill/the patient and the care-taker. (Senior Medical Practitioner, not within psychiatry, Semmelweis Hospital)

I think <the Director> works on a pioneer project to 'talk about mental symptoms'; they call us 'users' or 'experts of experience'. She taught me 'I learn from you, because I have the knowledge from the university, but you have the experience what you learn from your life-time, how do you feel, and what condition". (Patient at Awakenings Foundation HEA 3)

Although the patient being heard in the last quote has not experienced much attitude change among mainstream psychiatry, she did recount one positive experience of meeting a doctor who had been trained at the Awakenings Foundation Center, and how he was able to navigate the difficult relationship with her mother in a way that was conducive for improvement of her health.

---

6   Same word in Hungarian. Gender not specified.

The interviewed former leader of the anti-stigma group Nyitnikék, pointed to the difficulties in this area, but also some progress. The anti-stigma group has worked intensively to change the way media writes about mental illness with some success.

> *I started looking for similar initiatives in the world, and found some good examples in Australia set up by the government there. Their point was to impact on media towards communicating solidarity towards patients. It worked so that people could send them news that did not stigmatize or criminalize patients. We had to fight against such practices in Hungary, where media in criminal reports usually stated when a perpetrator had psychiatric problems. What they don't mention is that only max. 1% of perpetrators do… Depressed people aren't doing a lot, they are mostly hurting themselves. (Former Anti-Stigma Group, Nyitnikék, Leader, HEA 6)*

They have encouraged people to notify them about bad and good practices, and every year hands out awards to those who do well.

Ultimately, the goal of these activities is to change policy so that the approach taken Awakenings is taken up by other actors, both within and outside the state sphere. In order to do that, the Awakenings Foundation tries to be represented in forums where mental health strategy and policy is discussed, and has at least achieved to be invited to those. Whenever possible, users are taken to these forums as well. Some geographic up-scaling of activities has been seen over the years, and the Awakenings Foundation has also worked to support groups doing similar work in other cities. It has taken part in many dialogues around community-based psychiatry, although its impact on that is questionable given the little progress that has been done with mental health strategy development in general (see section 3).

The work of the Awakenings Foundation is recognized in the continued public contributions and private donations and willingness of affected to pay for its services. Recognition can also be seen in their continued leadership of the community-based mental health field in Hungary; as well as in the visibility and sheer variety of its initiatives. The organization's homepage (http://www.ebredesek.hu/) lists over a dozen conferences – mostly organized by the Foundation – specifically related to community-based psychiatry The SOLIDUS project team observed two conferences during 2016. Both were well-attended. The annual conference had 250 signed up participants, from all over the country, who for a modest fee (approx. 20 EUR) enjoyed a full-day program. The participants seemed to be mainly professionals from the social sector, but the conference also sought to involve relevant media by giving awards to those journalists who had produced the best reports in relation to mental health issues in the past years. Almost all recipients of these awards attended the event and expressed their gratitude for the price. An observed conference containing workshops on various best practices in different sectors also drew significant audience.

Although the subject of community psychiatry is seen as a niche, the Foundation is well-represented in mainstream media. Its somewhat outdated homepage lists nine newspaper articles between 2010 and 2013, but the closely associated anti-stigma group *Nyitnikék* has a much richer media archive (http://www.nyitnikek.hu/index.php?p=mediafigyelo) with up to one hundred links to reports that appeared between 2009 and 2016.

However, regardless of the scope and nature of participation, the organization does face problems of continuity in the long term. The Foundation has become synonymous with its Director, who does

most of media appearances and is the one identified by all clients interviewed for this project as the key person. Two of her family members are volunteers. Such reliance on charismatic personalities is not uncommon in the civic sector, but there were few signs of contingency planning to deal with this.

6. CONCLUDING REMARKS

Key to understanding the integrated approach to mental health advocated for by the Awakenings Foundation is to see the underlying assumption of what constitutes mental health and mental illness. If the line between mental health and mental illness is not sharp, struggles related to mental illness affect a far larger part of the population than otherwise thought. Likewise, if people can move between periods of mental health and mental illness in different times of their life, the potentiality for every citizen to be affected at one time or the other is much larger than if mental illness is seen as a personality trait. This approach leads to a call for increased solidarity and awareness between those who are currently affected and those who are currently not, recognizing that as time passes by, roles may be reversed.

This report has demonstrated how the Awakenings Foundation works to convince others of the virtue and efficacy of this approach: first, through their attempts to change social attitudes towards mental illness in Hungary, second, to involve both the patient, his or her friends and relatives in the treatment of mental illness and, third to widen the scope of public sector professionals who are willing and able to respond to mental health problems. During its 25 years of existence, the Foundation seems to have made progress in all three areas, while at the same time falling short of achieving (or contributing to) system-wise structural change. Working at the margins of psychiatry and at the margins of state-organized psychiatric care, it has played a key role in getting community-based psychiatric care placed on the map, and have used links across and within different professional groups to do so. However, greater impact would require major policy change accompanied by adequate resources, something that has still not happened.

Finally, some remarks on the importance of broader global and European developments for how the work of Awakenings Foundation has unfolded. An important research agenda is to investigate how European citizen and civil society solidarity-based activities react in times of austerity, state withdrawal and decreasing trust in democratic institutions. The study of Awakenings Foundation justifies three claims in relation to that in an Eastern European member state such as Hungary. First, the relationship between civil activism and the state has been both close and contested ever since its inception, and specific changes cannot be directly related to the financial crisis. Second, European and global influences clearly matter in that discourses and best practices have influenced both the policy agenda and the work of the Awakenings Foundation. However, this has yet to produce lasting and significant change. Third, recent European developments related to the relation between Hungary and the EU have had an effect on mental health through conflicts between the Hungarian fund and the managers of Norwegian EEA grants, which has provided crucial funding in this area. Prolonged negotiations led to several projects being significantly delayed. The frequently discussed measures to suspend European funding to Hungary due to nonconformity with EU values would likewise undermine the chances for alternative approaches to mental health to flourish.

CASE STUDY MATERIAL

Interviews

- HEA 1: Psychiatrist, Semmelweis University Hospital; background interview (represents stakeholder as the 'profession'), March 2016
- HEA 2: Judit Harangozó, Director of the Awakenings Foundation, March 2016
- HEA 3: Patient and Volunteer (middle-age, female), Awakenings Foundation, April 2016
- HEA 4: Patient and Volunteer (young, male), Awakenings Foundation, April 2016
- HEA 5: Social Worker, Awakenings Foundation, April 2016
- HEA 6: Former volunteer (2009–2015), Awakenings Foundation Anti-Stigma Initiative (*Nyitnikék*), April 2016
- HEA 7: WHO Hungary senior staff member; e-mail correspondence, May 2016
- HEA 8: Senior staff member, Department of Public Health, Ministry of Human Capacities, July 2016
- HEA 9: Senior Staff member, Department of Health Policy, July 2016
- HEA 10: Senior physician, Semmelweis University Hospital, October 2016
- HEA 11: Physiatrist, Semmelweis University Hospital, November 2016

Documents

Ébredések Alapítvány Közhasznúsági jelentések (Awakenings Foundation Annual reports 2005–2014)

Ébredések Alapítvány missziója (Awakenings Foundation Mission Statement)

Csontos, Erika. 2015. A pszichiátria Szent Grálja dr. Harangozó judit közösségi pszichiáterrel Csontos Erika beszélgetett <The Holy Grail of psychiatry. Talk on community psychiatry between dr. Harangozo Judit and Erika Csontos>. 2000. Iradalmi es tarsdalmi lap. Available at http://ketezer.hu/2015/08/a-pszichiatria-szent-gralja/ accessed December 8, 2016.

Participant observation

XVII. Közösségi Pszichiátriai, Addiktológiai és Mentálhigiénés Konferencia: Az (ön)segítés hatalma <17th Community Psychiatry, Addictology and Mental hygienic Conference: The power of self-help>, April 27, 2016.

XVIII. Közösségi Pszichiátriai, Addiktológiai és Mentálhigiénés Konferencia az Ébredések Alapítvány 25. születésnapja alkalmából: Eszmecsere a lelki egészségről és jó gyakorlatairól <18th Community Psychiatry, Addictology and Mental hygienic Conference at the Occasion of the 25th birthday of Awakenings Foundation, Practice exchange from mental health and best practices>, October 18, 2016

Works cited and consulted

Balint, Lajos, Peter Dome, Gergely Daroczi, Xenia Gonda, and Zoltan Rihmer. 2014. "Investigation of the Marked and Long-Standing Spatial Inhomogeneity of the Hungarian Suicide Rate: A Spatial Regression Approach." *Journal of Affective Disorders* 155 (February): 180–85.

Bálint, Lajos, Péter Osváth, Zoltán Rihmer, and Péter Döme. 2016. "Associations between Marital and Educational Status and Risk of Completed Suicide in Hungary." *Journal of Affective Disorders* 190 (January): 777–83.

Buda, Béla, Teodóra Tomcsányi, János Harmatta, Roger Csáky-Pallavicini & Gábor Panet. 2009. Psychotherapy in hungary during the socialist era and the socialist dictatorship. *European Journal of Mental Healt*h 4:1, 67–99

Dlouhy, Martin. 2014. "Mental Health Policy in Eastern Europe: A Comparative Analysis of Seven Mental Health Systems." B*MC Health Services Research 14* (January): 42.

Eurostat 2016. Health care expenditure. Available at <http://ec.europa.eu/eurostat/statistics-explained/index.php/File:Current_healthcare_expenditure,_2012_(%C2%B9)_YB15.png>, accessed December 8, 2016.

Gazdag, Gábor, Baran, Brigitta, Kárpáti, Miklós, Nagy, Zoltán. 2007. The History of Lipótmezö, the Site of the First Convulsive Therapy. *Journal of Electroconvulsive Therapy.* 23:4, pp 221-223.

Hungarian Government. *National Volunteering Strategy 2012-2020.* Available at http://2010-2014.kormany.hu/download/1/e8/d0000/N%C3%96S_eng.pdf

Hungarian Statistical Office. 2013. Yearbook of Health Statistics, 2012. Budapest: Hungarian Statistical Office.

OECD. 2014. "*OECD Health Statistics 2014. How Does Hungary Compare. Fact Sheet." OECD websit*e. Accessible at http://www.oecd.org/els/health-systems/Briefing-Note-HUNGARY-2014.pdf.

Rihmer, Zoltan, Xenia Gonda, Balazs Kapitany, and Peter Dome. 2013. "Suicide in Hungary-Epidemiological and Clinical Perspectives." *Annals of General Psychiatry* 12 (1): 21. d

Rihmer, Zoltán, Melinda Hal, Balázs Kapitány, Xénia Gonda, Márta Vargha, and Péter Döme. 2015. "Preliminary Investigation of the Possible Association between Arsenic Levels in Drinking Water and Suicide Mortality." *Journal of Affective Disorders* 182 (August): 23–25. doi:10.1016/j.jad.2015.04.034.

Rihmer, Z., W. Rutz, and J. Barsi. 1993. "Suicide Rate, Prevalence of Diagnosed Depression and Prevalence of Working Physicians in Hungary." *Acta Psychiatrica Scandinavica* 88 (6): 391–94.

Sebestyen, B, Zoltan Rihmer, L Balint, N Szokontor, Xénia Gonda, B Gyarmati, T Bodecs, and J

Sandor. 2010. "Gender Differences in Antidepressant Use-Related Seasonality Change in Suicide Mortality in Hungary, 1998-2006." *World J. Biol. Psychiatry* 11 (3): 759–585.

SOLIDUS. (2014). Grant Agreement, no. 649489.

Szanto, Katalin, Sandor Kalmar, Herbert Hendin, Zoltan Rihmer, and J. John Mann. 2007. "A Suicide Prevention Program in a Region with a Very High Suicide Rate." *Archives of General Psychiatry* 64 (8): 914–20.

TARKI 2016. *Fogyatékossággal élő emberek életminősége és ellátási költségei különböző lakhatási formákban* <Quality of life and cost of provision between different housing forms for people with disabilities > Part of the project 'New dimension in social protection towards community based living' http://www.tarki.hu/hu/news/2016/kitekint/20160408_fszk.pdf

Villadsen Nielsen, Louise Lars Hulgård & Jennifer Eschweiler. 2015. Working Paper on public policies in relation to solidarity and spatial cohesion/divide. *SOLIDUS project website*

World Health Organization. 2003. The mental health context. Geneva, World Health Organization, 2003 (Mental Health Policy and Service Guidance Package). Available at http://www.who.int/mental_health/policy/services/3_context_WEB_07.pdf

World Health Organization. 2014. An Assessment of the Hungarian Mental Health Care March 2014. Geneva and Copenhagen: WHO HQ and WHO Regional Office for Europe.