

# Changing the attitudes towards people with mental disorders – a shift in paradigm.

A pilot programme in Budapest

## GOALS

Awakenings Foundation is a Budapest-based nest and think-tank organization with the aim to shift the paradigm related to mental disorders in Hungary and Europe. During its development from 1991, the organization went through many stages, organically evolving from one to the other, all pointing in the direction of the main goal. The foundation launched several innovative projects as pilot programmes in Hungary.

### Specific goals - target groups

1. To improve human rights of users of psychiatric services. 'Awakenings Foundation' leads the way from dependency, misinformation, unfairness, to dignity, empowerment, self-confidence, free, conscious and responsible decision-making based on proper information.
2. Becoming a nest of NGO-s to improve self-help and advocacy work and increase civil involvement in decision-making in Hungary and Europe. Developing national and international networks on an NGO basis
3. Setting up recovery based community services in the social care for people with psychiatric disorders: a pilot model programme based on the values of recovery and the evidence of research – Target groups: users, families, professionals in the field
4. Antistigma Programme – Target groups: the public, the media, users, families, professionals

## PROJECT IMPLEMENTATIONS

Activities related to the programme are located in Budapest, but network also includes organizations from towns like Győr, Szekszárd, Debrecen, etc.

### 1. Human rights of users of psychiatric services

Our organization got involved in advocacy first when (1) working with MDRI (Mental Disability Rights International, USA) from 1995 –as Hungarian partner in their survey, contributing to the report published on the situation of the mentally disabled in Hungary (*Human Rights and Mental Health: Hungary*). Team of volunteers actively contributed to the success of the project. The same team got a training of the MDRI activists about international standards of human rights that were very far from the Hungarian ones at that time. (2)By a SOROS Grant, we funded the first nationwide organization to protect human rights of users of psychiatric services, led mostly by users and a representative of families and professionals, called PÉF (Pszichiátriai Érdekvédelmi Fórum –Mental Health Interest Forum) in 1996. (3) In 2000 leader of Awakenings Foundation with the leader of PÉF designed, developed and a public survey administered by a leading pollster institution to assess the situation and needs of people living with schizophrenia (n:200). The data collection was done by the activists of PÉF, mostly users and other volunteers. The results of this survey got great publicity in the media and professional literature as well, showing that people with schizophrenia can articulate their needs and opinions about services in a way that the general public can understand. Results showed that respondents need community based services and feel significant stigma and discrimination related to their disorder. Most of them received only pharmacotherapy that is still widely available in Hungary,

but no rehabilitation or psychotherapy, though the need for rehabilitation is very high. We continued our advocacy work with the leadership of PÉF as its member from 2000. We implemented an educational training material about human rights of people with mental disorders on our home page in 2004. We support users' advocacy and self help activities in several ways, including legal counselling by lawyers.

## 2. Becoming a nest of NGO-s to improve self-help and advocacy work and increase civil involvement in decision-making in Hungary and Europe. Developing national and international networks on an NGO basis.

Besides the foundation of (1)PÉF we encouraged and supported the foundation of two other organizations run by the families of people with mental disorders: (2)KESZ, Budapest, 1997, (3)Kálvária Egyesület, Győr 2000. Recently one more organization joined the circle: in 2008 (4)a new NGO, Gyöngysor Association run by users asked for and got the help of Awakenings Foundation in the process of the foundation and the launch. We supported (5)Szigony Foundation (from 2001) to set up a day club by the Fountain House model and vocational rehabilitation programme by the Supported Employment Programme standards. We support further NGO-s with value- and evidence-based methodology in the field of (vocational) rehabilitation and antistigma. We also built up a nationwide network of NGO-s in the field and implemented antistigma, community-based rehabilitation and human resource management programmes together. Our Foundation is also involved in international networks, including GAMIAN (from 2004), OTP (Optimal treatment programme, an international professional network working on a value- and evidence-based methodology of rehabilitation of people with serious mental disorders – from 1995). We are members of the WAPR (World Ass. For Psychosoc. Rehab.) and other international societies.

## 3. Recovery based community services in the (social) care for peoples with psychiatric disorders: a model programme based on scientific evidences and the values of recovery

The think tank nature of the organization began to flourish after the creation of its network of NGOs. The recovery based approach is encouraged to be applied towards chronic peoples in a democratic society with respect to human rights. The background is provided by the value-based and evidence-based community psychiatry model programme by the implementation of international Best Practices from 1996. Staff was trained by the International OTP trainers. We also used our international relationships that helped us to take part on trainings and study trips at several European and US centres. We set up the first social club programme by the Fountain House model and implemented community care programme as part of psychosocial service incl. family psychoeducation, stress management, skills training, and vocational rehabilitation programme by the method of Supported employment programme. Currently we serve 190 peoples and families in the community and 35 peoples in vocational rehab. programme. From 2005 we implemented a human resource management programme in the local community to develop a well functioning network of local social, health, vocational and other services, incl. various NGO-s. Consensus statements, training, case conferences were organized. With this background, we established the methodology and syllabus of community psychiatry in the field of social care professional training. Since 2000 we have been working as experts at the decision making level in the Ministry of Social Affairs and Work – being thus able to identify community psychiatric care service quality in Hungary.

**4. Antistigma Programmeme** within our five-year programme against stigmatisation: we ran a number of projects aiming to decrease stigma related to mental disorders. (1)The Antistigma Programme has developed its international network since its very start –eager to learn from international organizations and apply their Best Practices. We participated on the 2005 conference The Don Quixotes of the 21<sup>st</sup>-Century, organized by FEAFES Spain in close cooperation with Hungarian NGOs – and, vice versa,

our projects involve their participation in our events – such as the art exhibition in 2007. (2) In 2000 we went on a study trip to UMRHI Athens, the organization creating an outstanding programme against stigmatization in Greece. Antistigma Programme has different tools to reach out to the public: firstly the homepage of Awakenings Foundation ([www.ebredesek.hu](http://www.ebredesek.hu)) and the separate homepage of the Antistigma Programme ([www.nyitnikek.hu](http://www.nyitnikek.hu)), (3)secondly, the representation at various festivals (e.g. the Sziget Youth Festival). On the homepages we provide psychoeducational and stress management material which can be freely downloaded by those living with a psychiatric illness. On [www.nyitnikek.hu](http://www.nyitnikek.hu) we chose to apply a self-help approach to fight stigma. (5)We supported and helped the publication of the autobiography of a volunteer and user living with schizophrenia. During our festival programmes and according to our research, personal contact and meeting with a user are most effective ways to decrease stigma in the general public. By publishing the book we aim to provide the readers with the personal experience of a user.

(4) As for the theoretical background we took part in the international, multicentric stigma research led by Graham Thornicroft, and wrote an article about stigma and the projects applied to decrease it in Hungary.

Our future plans include the creation of a media-guide instructing the members of media in questions related to stigma and the initiation of an Antistigma award – to highlight the most stigmatizing appearances of the media.

## **KEY ASPECTS**

The shift in the paradigm and change of attitudes Awakenings Foundation aims to achieve comes through different but interacting innovative projects, a recovery based approach and evidence based technology. We want to apply the following objectives for users and families: full life in community, empowerment, no stigma, responsible service use, goal oriented services and need based service planning and evaluation. We spread our innovative initiatives through networks of NGO-s and other organizations with our mission of a thinktank and nest organization.

## **RESULTS**

### **1. Human rights of users of psychiatric services**

In 1996 the MDRI report was published with the help of Awakenings Foundation evaluating the situation of the mentally disabled in Hungary causing a great stir and raising awareness about the problem. Foundation of PÉF:1996, public survey in 2000.

### **2. Nest of NGO-s**

Five NGOs were founded and launched. Membership in 5 international network, local network with more than 30 NGO.

### **3. Value-based and evidence-based community psychiatry**

Freely available training material at home-page. Workbook of Community psychiatry, and supported employment programme, edited by the Foundation. Training programme for social professionals. Several publications by representatives of the F. Currently 190 peoples are participating in the community psychiatric care programme of the foundation, more than 400 users took part in the supported employment programme. Community psychiatric training for a few hundred social and health care professionals. Programme involvement in Social Act in 2000.

### **4. Antistigma Programme**

The Antistigma Programmeme volunteers have organized several festival-programmemes at the biggest youth festivals of Hungary since 2003. Hundreds of visitors came to our festival marquee run by 15 volunteering helpers, professionals and users. The article on stigma was published by the Hungarian EAAD (European Alliance Against Depression) member Institute of Behavioral Sciences, Semmelweis University, Budapest. Awakenings Foundation provides the Antistigma branch of the Hungarian EAAD since 2006. Free materials on self help, psychoeducation are available on the homepage of the foundation and the Antistigma Programme. A great achievement of the Antistigma Programmeme is that it pulled Hungarian NGOs together in the fight against stigma.

## **FINANCING**

Programmes of the foundation were launched in 1995. Since 1996 they were supported by tenders and helped by volunteer work. All members of the committed and innovative staff has volunteered for the organization but there are also real volunteers participating in different programmes. This last aspect is especially true for the Antistigma Programme whose workers are only volunteers. Since 1996 we won two Phare and a HEFOP tender – both being EU-based. Since 2005 our community pilot programme is financed by state budget. Help is also provided by financial support received from civilians and companies.

The Antistigma Programme started with the help of a 2003 Phare tender. The same provided funding for the foundation of Harmónia Klub and the Greek study trip. Since then different tenders, volunteer work and civilian support keep it the programmes alive. In 2007 e.g. two hundred Italian peoples visited the foundation's headquarter on their way to Beijing. During the reception the staff was volunteering, residents and friends provided the welcome-show. The tree planted during the reception – as a symbol of the friendship between the guests and the hosts – was a free gift from a nursery garden. All the representatives of the Ministry of Social and Health Care, the local council, the City Council of Budapest and the Hungarian Embassy of Italy (the Ambassador himself) came and joined the programme happily. The reception was sponsored by the Ministry of Health and Social Care and a supporter company.

The homepage [www.nyitnikek.hu](http://www.nyitnikek.hu) was constructed from a NCA (Nemzeti Civil Alap – Hungarian Non-profit Fund) tender.

## **ORGANIZATIONAL ASPECTS**

Until 2005 the foundation had only one full-time employee (the manager) and a part-time administrator, who worked in a one-room office. Apart from these others helped as volunteers. Since 2005 the organization works with fifteen employees and runs a 800 m<sup>2</sup> building, rented from Semmelweis University. This is the place where the professionals of the foundation provide health and social care – according to the principles of community psychiatry – for 200 peoples, in the framework of a day clinic.