Mental Health Situation in Bulgaria in the perspective of the Experts by Experience concept

Behavioural and psychiatric diseases affect people of all the countries in the world, causing suffering while influencing the economic and social situation. Persons, who suffer from these diseases, are often stigmatised and isolated, with a low quality of life.

1 General background

Bulgaria has a population of just under 8 million, which is shrinking at a rate of about 50,000 per year because of low fertility rate, rising mortality and emigration. Suicide rates are moderately high and stabilised, homelessness is increasing and unemployment is of dire proportions particularly in agricultural areas. The number of people with severe mental illness (SMI), living in institutions is appalling big, life there is miserable and with no hope for the future. So are the feeble protests that remain unnoticed of the huge number of retired people made dependent on very small retirement pensions and treated as outcasts. The number of destitute people with SMI is growing, as a result of the lack of understanding of the incapacitating consequences of serious mental illness in terms of needs for specific support and residential care.

People with mental illness are among the most vulnerable and excluded groups in society. They have the lowest rate of employment of any other disabled group; may have few friends or social contacts; family relationships have often been disrupted and too often they do not participate in any social, leisure and educational activities thereby spending most of their time in seclusion and solitude.

According to data from various reliable sources:

- at present, 10% of the world population suffers from a mental or behavioural disorder;
- it is estimated that 1 out of 4 people worldwide experience one or more psychiatric and behavioural disorders during their lifetime;
• neuropsychiatric disorders are also the most important causes of death among non communicable diseases, with higher rates than heart disease, stroke and cancer;
• depression alone has been ranked as the fourth leading cause of disability worldwide, directly after lower respiratory tract infections, perinatal conditions and AIDS;
• mental disorders are responsible for about 12-15% of the world’s total disability – more than cardiovascular diseases, and twice as much as cancer;
• their impact on daily life is even more extensive, accounting for more than 30% of all years lived with disability.

According to surveys, conducted by World Health Organisation (WHO) in different countries:

schizophrenia affects “… about 7 per 1000 of the adult population……The results of WHO study lead to a general and a bit unexpected conclusion that occurrence of schizophrenia type disorders is approximately the same in quite different from cultural, demographic and socio-economic point of view populations” It seems reasonable to expect a prevalence rate of at least 0.5 per cent for Bulgaria (about 36 000 people, assuming that the general population of the country is 7,204,687, as estimated in July 2009 ).

It is very difficult to quote exact mental health data for Bulgaria, because the country does not have a unified consistent policy for keeping statistics in this field. It is probably a heritage from the region’s communist past, when mental health has been treated separately from the general system of health care. It is peculiar, but even today, despite all reforms, that were implemented, aiming to abolish the outdated ill practices, psychiatric hospitals still have a different status from the rest of the medical facilities. While the latter were already registered as joint stock companies, mental health institutions are under the direct subordinance of the state, the health minister being their main principal.

Today psychiatric care in Bulgaria is provided in: 12 specialised psychiatric hospitals with a total capacity of 2790 beds; 12 psychiatric dispensaries with 1480 beds and psychiatric wards in general hospitals with a total of 717 beds. Taken as a whole, the number of beds has decreased (from 5555 in 2000 to 4035 in 2006, more recent official data are not available) at the expense of the number of beds for active treatment (reduced from 1091 to 995 respectively). The number of beds for day and home outpatient care has remained relatively constant.

According to WHO data, about 25-30 per cent of the initial contacts with the health network are an issue of mental distress. In Bulgaria the total psychiatric prevalence has risen from 2656.7 per 10 000 cases in 1990 to 2892.1 per 10 000 in 2004, after which it has dropped to 2287.7 per 10 000 in 2006. Regarding the so-called severe
mental disorders with a pronounced impact on social functioning, the diagnostic distribution is as follows:

- people with intellectual disabilities – 520.2 per 100 000 cases;
- people with schizophrenia and schizotypal personality disorders – 388.2 per 100 000 cases;
- people with affective disorders – 234.8 per 100 000 cases.

As for the common psychiatric disorders, which do not drastically impair the social functioning of the individual, but have a high incidence, data from the international comparative epidemiological research EPIBUL (conducted after the WHO initiative in 2006) of randomly selected samples of society, aged above 18, give a detailed overview of the situation in Bulgaria. For a one-year period in Bulgaria the common psychiatric disorders reach 20% of the total prevalence, which is among the highest levels as compared with the rest 7 European participating countries. The largest stake in this one-year prevalence falls to the anxiety disorders – 13.1%, followed by depression – 8.5%.

We should also consider the indirect effect of mental morbidity on key aspects of public life of the Bulgarians - the quality of life; the connection with the overall prevalence of somatic diseases (the so-called stress-induced diseases); economic loss incurred by mental illness. Although severe mental disorders affect a relatively small percentage of total population (1.5%), the dimensions of economic loss they entail are many times larger. This is explained by the huge social impact that they have on family and community - disability, involvement of social resources, secondary stress among relatives and friends due to high stigmatisation. The other significant group – the common psychiatric disorders also exert a negative influence in economic terms through the reduced work capacity and absenteeism due to comorbidities.

The analysis of the current practice of providing mental health services shows that the vector of efforts is directed primarily to dealing with the consequences rather than to preventing the onset of mental disorders. There are no investments in the development of programmes for early detection of prodromes of severe psychiatric disorders and for their prevention in family and work environment. On the other hand, coping with stress at work, in the community, family and interpersonal relationships is underestimated both at governmental level and at the level of mental health services.

The elaboration of the National Policy on Mental Health for the years 2004-2012, approved by the Government Decision, allows the creation of conditions for providing aid and protection, rehabilitation and social integration of patients with mental disabilities. This programme envisages a considerable improvement in accessibility and effectiveness of psychiatric care, by integrating persons with mental disabilities into the family and community through raising public awareness about mental health problems and mental disease recognition as one of the fundamental interdisciplinary issues.
One of the basic elements of the Mental Health Policy of the Republic of Bulgaria, adopted by the Council of Ministers in July 2004, is deinstitutionalisation and provision of alternative community-based mental health services. And yet, despite the officially declared good will for adopting the psychosocial rehabilitation approach for treating mental illness and a few sporadic initiatives, services, offered in the country, are highly insufficient - both in terms of number of programmes and capacity. To date, for the whole country, there are 11 functioning sheltered home programmes for people with SMI with a total capacity of 102 people and less than 20 day care centres for the same target group, each one with an average capacity of 25 persons.

However, evaluating the current situation, we found out that almost 4500-5000 persons with mental health problems still live in state social care homes and are placed under custody.

Experience with mental health reform in Bulgaria reveals that even though the vocabulary of community care has been taken on board and official documents have expressed political will for reforms, day-to-day practices and the quality of mental health care have hardly changed and remain a stronghold of institutionalism. Care for people with SMI is provided mainly in outdated institutions (hospitals, dispensaries, social services and social care homes), falling under the jurisdiction of two separate ministries (Ministry of Health and Ministry of Labour and Social Policy). All institutions work in isolation from each other, observing their own internal rules.

Currently there is no network linking these institutions and allowing for comprehensive care for people with SMI. As a result, care is done on an ad hoc basis and long-term planning is not possible. Individual work with clients has to start from the very beginning each time the person moves to a different institution, exhausting human resources and raising the cost of care.

Psychiatric stigma towards the people with SMI is a major destructive factor, undermining the lives of both mental health service users and their families in the country. It is the cause for social isolation and discrimination, and leads to violation of their human rights.

The long-term consequences of the existing situation are: permanent social isolation, dependence on institutional help, inability to compete on the labour market and a lack of social skills for the people with SMI, whether they live in the community or in an institution.

On this stage the social care and assistance of people with SMI in Bulgaria are almost completely left to their families which invokes high emotional and financial pressure for the family members.
Moreover, the lack of traditions and negotiating power of lobbying organisations, patients’ and relatives’ alike, impede the creation of a new organisational environment and structural changes.

In the view of main stakeholders the needs of people with mental disorders are:

a) **medical**: early recognition, information about illness and treatment, medical care, psychological support, and hospitalisation.

b) **rehabilitation**: social support, day care, long-term care, education, vocational support, spiritual needs.

c) **community**: avoidance of stigma and discrimination, full social participation, and human rights.

d) **family**: skills for care, family cohesion, networking with families, crisis support, financial support, and respite care.

Almost one-fifth (19.2 percent) of all Bulgarian psychiatrists, signed a contract with the National Health Insurance Fund (NHIF) to provide specialized **outpatient medical treatment**, work. The ratio of provision of psychiatric help (professionals/population) is higher than it is foreseen in the National Standards on (1/20 000). It is similar with provision of general practitioners (GP) services. On the other side, most of psychiatrists, who provide outpatient psychiatric services (according to their contact with NHIF), work also in other medical facilities, funded by the republic or municipality budget. Relationships between these two groups of professionals are quite formal, incidental and shallow. In spite of a serious number of psychiatrists, there is no wide range of outpatient psychiatric services available. Patients are offered a formal clinical assessment and prescription of medical treatment. There is very serious lack of other professionals, like psychologists, social workers and psychiatric nurses, working in outpatient psychiatric practices. Psychological and social interventions, a routine part of a comprehensive therapeutic and rehabilitation plan, are scarce.

We consider that people with SMI also could find their own place in society, based on their real desires and possibilities, rather than on their negative and unrealistic image, as long as they get an adequate help and opportunities to develop and invest their potential.

Although some serious attempts were made, psychosocial care, provided for people with SMI is still not enough, but the first steps have been taken and we hope that the process of transformation will gradually take place.

**Follow up steps towards solving the above-described problems**

- Real involvement of the government institutions in the implementation of the tasks from the already adopted Action Plan according to the National Policy on Mental Health
- Intensification of the work of the National Council on Mental Health
2 Examples of Experts by Experience practice in Bulgarian setting

The Experts by Experience concept is a pristine area in Bulgarian practice, particularly pertaining to severe mental illness. For a number of decades most psychiatrists and other mental health professionals have fostered the idea of their own omnipotence and omniscience. The capacity of the client has been completely underestimated. The general attitude of society has been that the specialists have gone through educational courses and training and, therefore, they are the ones who should be trusted and should always “have the last and only say” in taking decisions for the lives of their clients, who have been perceived as voiceless receivers of care. However, recently, the solid image of the almightiness of the PROFESSIONAL has started to crack. In the field of mental health, attitudes of the experts by training have undergone significant change over the last 5-6 years. They gradually opened up to the idea that the users of services should be treated as equal partners in the process of their own treatment. They have the right to ask, to demand explanations about their condition, to insist on information about the different alternatives. They should be encouraged to assist the professionals and actively contribute to their own recovery. The idea of informed consent became central in the ethic codes of the professional community. Referring to severe mental illness, professionals adopted the concept of constant learning from practice, of flexibility and needs-based treatment, individual approach to the client. Some of
them went even further in innovation – admitting their lack of knowledge on some highly specific aspects of the condition of mentally ill patients – such as hearing voices and effects of medication, they welcomed the possibility of learning from the patients. More and more professionals gradually started to realise that they suffer a shortfall of knowledge which can be gained only through experience. The realistic expectation is that this recent approach will soon take precedence and will be widely accepted and integrated in the educational courses for mental health professionals and in practice as well.

To date, there are some individual initiatives but no coherent and systematic routine in the direction of implementing the experts by experience concept.

2.1 Sporadic initiatives of inviting people with mental illness to talk to medical students in the course of their lectures in psychiatry

Regrettably, this routine has not been stipulated as a compulsory element of the Medical university training courses. Neither is it defined as such, nor is regulated in any manner. These meetings are informal by character and take place on an ad hoc basis, depending on the personal discretion and good will of the lecturers. As might be expected, the psychiatric patients, who are invited to these classes, are referred to as “animals in a zoo”. They are not explained what the purpose of these “visits” will be, nor are they prepared and tutored how they should present their experience, so that the future psychiatrists could benefit from it and enhance their professional competence. The usual practice is to take a patient from the University psychiatry hospital and take him/her to the lectures to “show up” and answer the students’ questions, and probably share some personal experiences. The problem is that the meetings occur irregularly and randomly and are not shaped as a regular and mandatory fundament of the psychiatry course. These haphazard routines could be developed further in several directions:

1. elaborating a special course for training people with mental illness as Experts by Experience with the aim to serve as co-lecturers of medical students;
2. “upgrading” these meetings into an obligatory and sustainable element of the university course;
3. adapting of the existing university training programmes for mental health professionals so that lectures with EE are incorporated in the educational course, with view to facilitating the learning process, particularly when introducing some mental conditions which are difficult to comprehend without personal experience, such as hearing voices, first psychotic episode, depression, bipolar affective disorder, effects of psychiatric medication, etc.;
4. lobby and advocacy for accrediting the newly adapted programmes by the respective academic institutions.
### 2.2 Contracting people with mental illness in the role of EE as regular staff of some mental health facilities

Frankly speaking, we came upon only one example of this routine and it cannot be said to fully implement the EE concept. **Chovekolyubie/the Bulgarian word for Philanthropy/Association** in the town of Pazardjik has established a Centre for mental health, comprising psychosocial rehabilitation programmes, crisis interventions service and a social enterprise. The latter includes: a studio for manufacture of souvenirs, shop for honey and bee natural products, a refreshment booth, scraps collection point and a vegetable garden. The philosophy of Chovekolyubie Association is that every user of the services, provided by them, could become a part of the staff as long as some requirements, which are crystal clear and known by all team, are fulfilled. Transparency, equal treatment and equal opportunities are among the guiding principles of the organisation. The Association has always had users of mental health services among the regular staff of the Centre for mental health. Usually, the users are hired after the employment schemes of the Labour Bureau Directorates (structures functioning under the subordinance of the National Employment Agency with Bulgaria’s Ministry of Labour and Social Affairs). They are 5 to 11 people with SMI hired at Chovekolyubie at any moment of time. However, most of them are not in an EE position. These are just regular jobs such as gardening & maintenance, cleaning, etc. As for the EE jobs, these are a **vocational therapist** and **social affairs assistant**. A user or a relative of a mentally ill person can occupy the aforementioned positions. At the time of preparing this document, there were 5 users appointed at these two positions working under labour contracts through the national employment programmes. As far as training is concerned, it is conducted **ad hoc** – whenever an opportunity springs up. For instance, when the Association has an invitation for a seminar (very often it is carried out within some project by a partner organisation -Bulgarian Helsinki Committee, GIP, Open Society, etc.), the “experts by experience” are sent to attend it with view to enhancing their capacity. No special educational course has been designed for EEs. Nor does any systematic education for EEs exist. Training is performed on a random basis, depending on the individual and the situation, which is extremely time and efforts-consuming, not to mention that this approach does not guarantee high quality. For example, when the Labour Office Directorates organised professional qualification courses for Social Affairs Assistants, a total of 15 people from Chovekolyubie’s Centre for mental health went through them, then sat for an exam, and were awarded certificates.

Bulgarian Helsinki Committee developed a 6-month course in civil education and wanted to invite people with disabilities in a way to receive a sort of EE training, but the initiative could not be implemented because it did not get finance.

Training-wise, so far, there have been only separate attempts, one-off initiatives and nothing purposeful, systematic and sustainable. The alleged experts by experience were left to themselves – “to climb the ladder of self improvement”, as Chovekolyubie staff put it. They went on to explain that they have assumed the pay-
it-forward principle, i.e. whenever a member of the team has a specific knowledge, s/he should convey it to the others.

Furthermore, the EE practices in Chovekolyubie’s Centre for mental health developed a tendency to deviate from the original purpose. For instance, an ex-teacher with mental illness is presently hired as a vocational therapist, but it is not because of her EE skills. The emphasis is laid on her specific practical skills – such as skill to prepare invoices, knowledge in accounting, cleaning skills, etc. And she ended up being a seller at the honey & bee natural products social shop. Some time ago, they hired a user to write a book about her personal first-hand experience with severe mental illness, but they did not contract her for her competence as an EE, but because of her former career as a journalist. However, the initiative did not succeed because the user did not receive any training as an EE nor adequate support.

In conclusion, it is beyond any doubt that in order to efficiently implement the EE concept, a specially-designed training for mental health users to serve as EEs is needed.

The Labour Bureau Directorates (LBD) could be a reasonably-priced mechanism to this purpose. According to law, whenever an employer wants to provide an extra training for the staff, so that they can get a certain skill/ knowledge, which is needed in their work, the employer can apply with LBD and, if approved, the LBD and the employer can share the expenses for the training course. Then LBDs hire companies, registered and licensed with the National Agency on Professional Education and Training (NAPOO) to develop the necessary training programme, to conduct the seminars and give a certificate.

[The only requirement is that the employees trained should have worked in the organisation for a minimum of 3 months before the course and must stay in the job for at least 6 months after that.]

Translated to the EE issue, this means that the development and implementation of training programmes for EEs could be partially financed by the government.

2.3 Vocational rehabilitation programmes for people with mental illness/
Supported employment programmes

Psychosocial rehabilitation is a comparatively new notion to Bulgarian setting. It was less than a decade ago when professionals in the country first started talking about its benefits and about the various programmes and tools for “enacting” this concept. By transferring knowledge and involving users in the processes of planning related to their case management plan, they develop their capacity to participate and make decisions. Establishing of “Patients Councils” was a way to stimulate users to express their position, accentuating on their possibilities and not on their problems and deficits. It rendered better outcomes of the care, provided by professionals. What is more important, the users improved their negotiation skills and specific abilities with regard to relapse prevention and everyday management of the
symptoms. In addition, by having the chance to acquire some basic skills in using computer, for instance, the users increased their vocational capacity and competitiveness on the job market. Through participating in supported employment programmes, the beneficiaries could integrate in the community and expanded their life perspectives. An immediate effect was the decreasing of the burden of care for relatives of people with SMI.

However, we should draw a clear-cut distinction between vocational rehabilitation programmes & supported employment schemes for mentally ill people and Experts by Experience concept. There is some cross-reference with view to acquiring and/or restoring working skills, which are needed in both cases, but the training for an EE necessitates a wider educational scope. Moreover, it also involves finding or even creating an eligible employment opportunity.

Vocational rehabilitation and supported employment aim at finding and maintaining any job, whereas the EE programme narrows down to getting a job in a very specific position.

In this sense, we can talk about job-searching and keeping programmes, but EE training programmes, defined as such, are not present in the country.

*The EE concept is better covered and has long-established traditions in the field of substance abuse and HIV/AIDS.*

### 2.4 Communes for treating drug addictions

There are various examples of ex-drug addicts employed as regular staff at facilities oriented to treating drug addictions (particularly heroin abuse), such as the *Commune in Bunovo* (where the owner is an ex-drug addict) and the *Phoenix therapeutic community*.

The idea is that ex-addicts who have successfully passed though the treatment course and have been ‘clean’ for a minimum of 2 years are welcome to become a part of the staff in an EE role. In light of this, the therapy course is equalised to an EE training course. As a matter of fact, we have found out that in most communes it is obligatory to have at least one ex-user among the staff, which entails the following positives:

- Ex-users already know the mechanism of treatment, the logic and sequence
- They have valuable knowledge, gained through personal experience
- They are well accepted by the rest of the team
- They have a robust personal motivation – to help others like them

These EEs work as full members of the clinical team. They take part in all staff meetings, share personal experience and even give advice to professionals whenever relevant.
Unfortunately, sometimes they come back as patients, but this is a risk, which is inherent to the nature of their previous condition.

In conclusion, we can say that communes for drug addicts are an example of very successful implementation of the EE concept.

2.5 Anonymous Alcoholic (AA) groups
Self-help groups are the traditional application of the EE idea. However, they do not offer employment. There are four real AA groups in Bulgaria – three in Sofia and one in Bourgas and four virtual groups (by e-mail).

2.6 I Foundation – acting in the field of HIV/AIDS
I Foundation maintains a counselling cabinet for people living with HIV, located in immediate proximity to the premises of the facilities for HIV/AIDS treatment in the town of Varna. The counselling cabinet gives information and consultations on antiretroviral treatment, ensures support for receiving adequate medical services, provides help by a social worker and lawyer, as well as psychological consultations. They also have various training materials, covering broad aspects of the nature of the illness and living with it.

I Foundation maintains a pool of clients who are trained to work with other clients in their capacity of EEs, always accompanied by a professional. It is important to note that they are not hired with labour or freelance contracts, neither are they paid for their services. The EEs work on a voluntary basis.

The professionals from the counselling cabinet often refer to the EEs: “Who else could know better but them? They are experts”

However, there is no congruent, consistent and formalised system of training for these “experts”. The I Foundation relies on ad hoc initiatives – usually with the Ministry of Health (MoH). The EEs from the counselling cabinet are invited to all seminars that are organised by the MoH or the I Foundation. On a number of occasions, reputable lecturers from various mental health and medical fields have been invited to deliver presentations (doctors, psychologists, etc.) and EEs had the opportunity to attend those educational events.

2.7 Initiative for Health Foundation – acting in the field of substance abuse and HIV/AIDS
Initiative for Health Foundation (IHF) is a non-governmental organisation established at the end of 1997 by several professionals in the field of drugs. The main goal of the organisation is to assist society in finding an adequate response to the drug phenomenon and to work for the development of a wide range of services and support activities oriented to drug users. The main activities of Initiative for Health aim at reduction of the health and social harm, related to drug use; prevention of HIV/AIDS among out-of-treatment drug users and among especially vulnerable groups, such as sex workers and Roma community; training of professionals and
volunteers in HIV/AIDS prevention among injecting drug users; research projects in the field of drug use and HIV area; advocacy efforts for effective policies. Since 1998 the organisation has carried out an outreach programme for prevention of HIV and other blood transmitted infections among out-of-treatment injecting drug users, and since 2001 – among sex workers. In 2003 Initiative for Health opened the first drop-in centre for drug users in Sofia, and in 2006 – a second one in the Roma community. In 2008 a methadone maintenance program was started in one of the centres.

According to IHF’s policy, vision and practice, there should always be at least one Expert by Experience in an outreach team.

The EEs with IHF work as outreach workers – they provide consulting, dispense materials and receive payment for their services. They are contracted as regular members of the team, have job descriptions and go through training. These are internal trainings, comprising theory and practice.

Currently, there are 2 people hired as EEs with the foundation, but they used to be more in the past.

“Nadezhda /the Bulgarian word for ‘hope’/ – Sofia” Foundation carries out similar activities and also employs EEs.

2.8 Separate initiatives – psycho-education seminars

And, finally, there are some “apocryphal initiatives” with dubious effect and quality-laying stakes on personal negative experiences. These initiatives envisage organising seminars purporting to help people increase their self-awareness, re-work the trauma in a healthy way. The training programmes of the events are not accredited by any of the reputable large educational institutions and are usually carried out by foreign people. The people who successfully pass the “educational course” are believed to be able to provide help to other people in their capacity of EEs. The reason of mentioning these seminars here and not dumping them as sect-like phenomena, is that they enjoy a keen interest and attract a lot of participants, and what is most important: this interest reflects the need of EEs practices. For instance, every year in November there is a seminar, named “Essence”, which is publicised through not quite official channels. The paid 5-day psychological training is conducted by a therapist from the UK. The aim of the seminar is “through personal experience (most often in loss & bereavement) to reconsider it and extract the essence of life”. The training is tailored to the needs of the group and includes introductive lectures + roleplay + work in small groups on artistic visualisation, self-reflection, etc. The best performing participants in the training could subsequently become assistants to the UK trainer, but they do not get payment for this. Or they could help on their own to other people who have gone through the same traumatic experience.
The average disability pension of person with mental illness per month is around 100 leva (appr. 51 Euro) which is under the existential minimum. At the same time the social services have restricted their functions to distribution of small financial assistance in accordance to bureaucratic procedures which do not take into account the individual needs other than money; additional difficulties are related to the refusal of the social services to provide psychiatric home care.


http://www.mh.government.bg/doc/standart_psihatrig.doc