The care of people living with mental illness in the Hungarian social care system: The process of deinstitutionalization and the phenomenon of stigmatization

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Purpose: The aim of this study is to present a situation assessment within the framework of a comprehensive study of the social services for people with mental illness in Hungary. After setting the historical background, we describe in detail the current services, their anomalies, and the ongoing implementation of a strategy to deinstitutionalize them. *Materials and methods:* We reviewed the related academic literature and systematically collected and elaborated upon legal documents, decisions, and data from national databases. *Results:* We established that a paradigm shift is taking place in the social care of people with mental disorders in Hungary. The lack of human resources, the paternalistic, institution-centered attitude, the mass supply of social services in dilapidated buildings, and the stigmatization of patients are among the greatest problems. Cooperation between the health and social sectors is inadequate and, in the interests of patients, needs to be improved. *Conclusions:* Hungary needs a complex, integrated, health-and-social-care supply system for people living with mental illness, one that takes into account both personal needs and assistance to recovery. In the continuation of the deinstitutionalization process, emphasis should be placed on social sensitization.

Keywords: mental patients, social care system, stigmatization, rehabilitation, recovery

INTRODUCTION

Tending to patients diagnosed with mental diseases places a serious strain on societies, even those with a more developed culture of health care. On certain levels of the care system, patients with a chronic mental disease have to stay in contact with a number of service providers throughout their entire lives. Only a sufficiently regulated and integrated care system can guarantee mental patients access to adequate treatment, tailored to their personal needs, through every stage of their illness [1]. In the European Union (EU), most long-term services – such as residential homes, institutions for nursing and care, and services connected to residence and clubhouses – belong to the field of social services.

Mental patients in Hungary are present in both the health care and the social care systems [2]. On the level of basic services, legal regulations [Decree no. 1/2000 (I.7)] in Hungary now require social institutions to cooperate with health care service providers – in particular, with the patient's physician and house practitioner – when they care for mental patients. Accordingly, more actors are beginning to share the responsibility and involvement. Based on international experience, however, intersectoral cooperation seems to face considerable barriers [3]. In this article, we present a comprehensive study of the social services for people with mental illness in Hungary. After setting the historical background, we describe in detail the current services, their anomalies, and the ongoing implementation of a strategy to deinstitutionalize them. We conclude with a situation assessment.

MATERIALS AND METHODS

We reviewed the literature on the antecedents and development of the current Hungarian social care system as a framework in which to focus on and assess the current situation for people with mental illness. Using the Hungarian Social Users Registry and the Hungarian Social Services Registry, we reviewed the system's services in detail up to the 1993 Act III on social administration and social services, and we collected the system's anomalies. We reviewed government decrees and public-tender documents concerning the government strategy known as the Deinstitutionalization Program, and we reviewed the relevant literature on European good practices.

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RESULTS

Historical background

From the middle of the 19th century until recently, providing treatment for mental patients was commonly regarded throughout Europe as a task to be performed by the health care sector. By modern standards, there was no social care system in Hungary until the 1950's. The system of social services providing support for the disabled was not established until the 1970's and 1980's [4]. Institutions dealing with mental patients struggled to keep their headcounts throughout Hungary in the 1950's, as discharged patients quickly found themselves back at the institutions. It was revolving-door treatment. In many cases, there was no home to send the patients back. Expansion of the institutions became inevitable. Palaces previously owned by noble families and later socialized by the communist regime often served as schools. Granaries and other agricultural buildings served as foster homes for children and provided residential care for the older people, the disabled, and the mentally ill [5].

In Hungary, it is the state's responsibility to ensure personal care (encompassing basic and specialized services) for people in such need. Basic social services include village caregiving services, home assistance, meal provision, family support, alarm-system-based home assistance, community services, support services, street social work, and day care for various groups in need. Specialized services, within the framework of residential care, include the so-called institutions for nursing and care, temporary homes, institutions for rehabilitation, and residential homes. As of January 1, 2013, supported housing also belongs to the circle of specialized care, although it is not considered institutional care. In the following, we will try to present the basic and specialized services.

Basic services

Community-based psychiatric care for mental patients was officially introduced in Hungary within the system of social services in 2003. Its introduction was preceded by a model program. The Hungarian legislature then deliberately broadened the circle of basic services for mental patients (besides community care services for people with addictions and support services for the disabled).

The services primarily target mental patients not posing any danger to the public, patients who receive psychiatric treatment at home. With the help of specialist care, their illness can be maintained in balance, but their conduct of life, their rehabilitation, and their social security can only be optimally supported by community care, based on their individual needs. The goal is to make community reintegration of clients a reality in order to help them become full members of society. All aspects of a complex psychosocial rehabilitation are provided in the living environment or home of the patient. Patients receive support in resolving their problems, retaining and improving the skills and capabilities they possess, coping with everyday conflicts between their social and mental care, and furthering their access to health care services.

Community caregivers help clients in identifying and reaching their personal goals. These caregivers typically attempt to rely on community resources as much as possible, especially the participation of relatives, and other "natural helpers." In the course of community care, the concerted cooperation of social and health care professionals is often necessary. Through intense case-management activity, the service ensures a strong bond between the care systems and the individual. Their target is the most complete recovery of their patients.

Day care includes services for mental patients who do not require inpatient hospital care or placement in a residential social institution. They can also be used by people in crisis, as a preventive measure. These services, which clients can choose voluntarily, include the provision of meals, basic hygiene facilities, and the facilitation of their social connections. Building on self-reliance and self-support, day care also organizes cultural, recreational, informative, educational, public, and family programs, according to clients' needs. Based on their needs, an individual care plan is prepared for them, to ensure their rehabilitation and recovery. This individual case management makes it possible for them to develop and manage their life and social skills, human connections, and free-time activities, and to find employment. Day care is basically an open form of care, which is capable of reacting to needs quickly. It can be used as an integrative tool to provide a secure background to the interconnection of different basic and public services at the municipal level.

Specialized services

Institutions for the nursing and care of mental patients provide treatment for those patients who are not in need of inpatient hospital care and are not a threat to public, but who are not self-reliant because of their health condition or social situation. Residential institutions offer non-stop, all-around care, including meal provision, medication, mental treatment, sociotherapeutic treatment, work therapy, skill building, and educative programs.

Rehabilitation institutions for mental patients offer treatment for those patients who are not in need of regular or acute hospital care, but for whom there is no other form of aftercare. Based on an individual rehabilitation plan, these institutions offer consultation regarding life skills, support for mental and social problems, and help in finding employment. These services rehabilitate the patients by giving them the skills necessary to live independently.

Residential homes for mental patients, which operate only for the purposes of rehabilitation, can accept only 8–12, or under exceptional circumstances, 14 patients. They provide services tailored to the patients' age, state of health, and the degree of their self-reliance. To be placed in a residential home, patients must be at least partly self-reliant, and must have been declared fit for living in such an institution.

The base of modern social services: supported housing

Supported housing refers to a quite new form of service that provides persons outside the traditional institutional framework with housing and social services on the basis of age,

health condition, and level of self-sufficiency. Using a case-management technique, social workers follow their mental hygiene and changing life conditions. Supported housing service provides support only to the extent it is individually needed; therefore, it fosters self-sufficiency by the means of social work. Instead of providing residential care in a ready-made "package," supported housing includes a flexible combination of different forms of housing and assistance services, which are provided on different premises. Service provision is based on a complex assessment of individual needs and the accessibility of other services within their living environment. It specifies the necessary support corresponding to all these conditions, taking into consideration that informal and professional support networks are key elements.

During the 2007–2013 period of deinstitutionalization, supported housing could be established with a maximum of 25 beds; currently, it can be provided only in a house or apartment accommodating a maximum of 12 persons. To facilitate deinstitutionalization, a group of apartments or buildings for accommodating a maximum of 50 persons can be established with the conditions that, besides housing, no other social services can be provided, and that housing cannot be created in neighboring apartments or houses in order to reinforce integration. Supported housing services cannot be established and maintained being disconnected from the settlement; therefore, they must be integrated into the city or village. It is a principle that clients spend time outside the house, both by using community-based services and by spending their spare time outside.

Dysfunctions within the system of social care

The system of social services has been changing continuously and significantly in recent decades. The availability of basic services (community-based services) has become mostly ensured for mental patients (Table 1).

However, the social services system works with many anomalies. The most problematic are the nursing-and-care homes in 150–200 years old castle buildings. Table 2 shows the problems that complicate the functioning of certain social services and recommendations for their solution.

Nursing and care homes for mental patients are fundamentally institutions [6], where loss of skills and hospitalization generally take place a short time after a patient is admitted. In these homes, the dominant theme is linked to the traditional, strongly paternalistic situation remaining from the socialist era, and the biomedical model of health care. The main element of care is the administration of large doses of medicines having adverse effects. Mental patients admitted to long-term care institutions gradually lose their self-sufficiency, they do not make responsible decisions, and they have to live their lives without the possibility of leaving the system of institutional care. It is a fundamental problem that the employees of the institutions do not believe recovery of the residents is possible. Unfortunately, long-term improvement in the condition of the mental patients is not a target, and recovery is not manifested as a real objective [6]. More than 8,000 psychiatric patients in 75 large nursing-and-care homes are waiting for deinstitutionalization (Table 1).

History of deinstitutionalization

Following the 1990's democratic transition in Hungary, there was a growing demand that care for the disabled be provided in small groups, based on individual needs. In the following decades, a significant paradigm shift has taken place throughout Europe, where policies have come to support the social community, rather than the medical–institutional approach to caring for persons with disabilities, psychiatric diseases, or addictions. As a result, the focus has shifted to promoting the patient's community and social inclusion and creating or facilitating a lifestyle as independent as possible. The commitment to decommissioning institutions providing care for a large number of people was an important step in this process. Over the past two decades, restructuring of such institutions has been the subject of both Hungarian and international legislation.

In 1998, The Hungarian Disability Act was enacted. It contained provisions relating to a deinstitutionalization project that had begun earlier that year and authorized a call for tenders, to be paid from both Hungarian and EU funds, to develop several residential homes per year and specialized forms of community and social services that would provide personal care for the disabled through 2006.

By 2001, the Hungarian buildings in which residential social care institutions had been established in the 1950's were badly in need of reconstruction, and the 2001–2009 Mansion Program was begun in order to ensure a better and more livable environment for care recipients until the buildings could be replaced. Moreover, between 1998 and 2006, local governments could use a targeted support system to submit claims for priority-development allocations, and the parties concerned could also apply for the renovation of social institutions. In the framework of the

Table 1. Governmental basic services and residential institutions for mental patients

Type of service	Number of institutions	Number of clients/residents
Community care for mental patients	91	4,770
Day care for mental patients	100	3,854
Temporary home for mental patients	7	101
Residential home for mental patients (rehabilitational)	13	189
Rehabilitational institution for mental patients	7	128
Supported housing for mental patients	28	417
Nursing and care home for mental patients	75	8,069

Note. Source: Hungarian Social Users Registry, Hungarian Social Services Registry, December 13, 2018.

Table 2. Anomalies of social services and recommendation for development

Type of service	Anomalies	Recommendations
Day care for mental patients	Very few day care institutions, waiting lists, different professional programs, failed rehabilitation in many cases	Increasing the number of day care institutions, sanctions for contravention of law*, standardizing professional programs
Community care for mental patients	In the countryside, there are difficulties due to distance between settlements, low number of professionals with adequate competencies, time spent on travelling by public transport. Extended administrational burdens reduce actual care time	Increasing the number of services, improving competence-based training, increasing the level of training, reducing administration (bureaucracy), options for a service car in the countryside
Temporary home for mental patients	Low number of beds, altering the original goals, actually replacing beds of long-term nursing and care institutions	No recommendations, this service form has ceased to exist, even legally
Residential home for mental patients (rehabilitational) Rehabilitational institution for mental patients	There are few results, the content of rehabilitation is being drained, the focus is placed on preserving, individual rehabilitation is not the aim, lack of well-educated, and competent rehabilitation professionals	Reviewing and reengineering the operation of rehabilitation institutions, person-centered and individualized rehabilitation, and development of rehabilitation specialist training
Nursing and care home for mental patients	Overcrowding, constant lack of resources, hospitalization, institutions in geographically isolated areas; neither the material, nor the personal conditions of the institutions are secured, high fluctuation, the very incomplete knowledge of caregivers, several fundamental rights are violated (the right to human dignity, the right of self-determination), and irreversible social isolation	Faster and more efficient implementation of the deinstitutionalization process more appreciation and the raising of wages, a career model for caregivers/nurses, basic renovations of buildings for improving operation, real checks and continuous professional control, and development of financing
Supported housing for mental patients	Hostile citizens, lack of acceptance, stigmatization, few job opportunities	Anti-stigma programs, right information for community, motivating employers

Note. *Despite the fact that it is a compulsory task for every local government with a population of more than 10,000 persons to provide day care service for mental patients, the number of these services lags behind the desirable level.

program, it was possible to replace institutions that could not be renovated or operated economically by investing into new facilities. The allocations, however, were ad-hoc and not of substantial size. In several cases of large, long-term institutions, quick fixes were implemented when decommissioning would have been a better solution.

Hungarian projects reflected new European policies that supported, where possible, the social community rather than the medical–institutional approach to caring for persons with disabilities, psychiatric diseases, or addictions. The focus of care moved to the promotion of community and social inclusion and the creation or facilitation of a lifestyle as independent as possible. The partial transition from an institutional health care system that cared for a large number of people to a community social care system was an another important step.

The Disability Act is regularly updated. In 2010, it was updated to prescribe that institutions providing nursing and care services for over 50 persons with physical or psychosocial disabilities (mental patients) must be replaced. In 2011, it was updated to prescribe that replacements for social care institutions could be created only in the form of residential homes. Residential homes for disabled persons and mental patients clearly represented a shift towards community-based services besides day care institutions and laid the foundations for further deinstitutionalization. This was another major step with regard to changing over to community-based services.

In 2007, Hungary was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities

(CRPD). Accordingly, Hungary recognized – besides other rights – "the right of all persons with disabilities to live in the community, with choices equal to others," and recognized its responsibility, according to Article 19 of the Convention, to "take effective and appropriate measures to facilitate" this. The CRPD right to free decisions is substantial, as it must be possible for disabled people to be completely involved in the community. For clients should be given the opportunity to: – balance the aspects of community life; but not subordinated to them – make free decisions about their lifestyle, such as agenda, interior design, meal, outdoor programs, job, and choosing roommate [7].

In 2011, the Hungarian government adopted a 30-year strategy that included creation of the National Body for the Coordination of Deinstitutionalization to coordinate and implement its policies. The goal of the strategy is to replace social institutions providing nursing and care for people with disabilities with community-based housing arrangements and services. The direct target group includes disabled persons receiving care in an institution providing care for a large number of people. The target group also includes disabled persons with addictions or psychiatric disorders.

Implementing the strategy in the light of financial support

In the first 3 years of the strategy, restructuring of institutions was realized in the framework of a project entitled "Social Infrastructure Operational Program – Replacement of Residential Institutions – Social Institutions Component,"

which had a budget of HUF 7 billion. The project's goal is to replace the capacities of residential social institutions having more than 50 capacities offering care and nursing to persons with disabilities, psychiatric diseases, or addictions, according to principles defined by the strategy. By 2015, from a total of HUF 5.8 billion, 672 supported housing capacities were created from 6 institutions, out of which 120 beds for mental patients were deinstitutionalized. Because of broad professional and civic participation, in 2017, the government updated its strategy so that its goals were expected to be reached in 2036, 5 years earlier than originally planned. The vision was elaborated by summarizing the experience gained in recent years, adopting a human rights approach, and taking into account recent legislative changes, focusing on community-based care. It describes the replacement of 10,000 capacities.

The deinstitutionalization process continues during the EU's 2014–2020 financial cycle. Three EU projects are under way, collectively entitled "Promoting transition from institutional care to community-based services" (with code numbers EFOP-2.2.2-16, VEKOP-6.3.2-17, EFOP-2.2.5-17, to designate the regions), with a budget of HUF 89 billion. The projects are aimed at the complete transition of institutional service forms having more than 50 capacities offering care and nursing to persons with disabilities, psychiatric diseases, or addictions, and at the creation of community-based service forms of high quality, responding to residents' needs.

With deinstitutionalization to access the recovery

Determining the number and needs of people with a psychosocial disability (PSD) is difficult [5] because the definition of a person with PSD is difficult. By one definition, a person with a PSD is any person who has a long-term mental impairment that may limit – along with several other handicaps – the person's complete and efficient involvement with others [8]. In Hungary, there is still no consensus on the extent to which psychiatric diseases may cause disabilities.

Nevertheless, the process of deinstitutionalization – in accordance with the CRPD – continues. In several countries, the large, closed institutions have ceased to exist. In Eastern European countries, especially in the new member states of the EU, this process is in its first phase. The deinstitutionalization programs in many countries have had a positive effect on services, e.g., the accessibility of community-based services or social services [9]. Generally, the institutions were closed in line with development of the networks of services and the modification of related policies, e.g., in the United Kingdom, Greece, Italy, and the Netherlands [10].

During deinstitutionalization in Hungary, only the isolated development of social and other community services has taken place. There has been no national and comprehensive process to provide services to those who have been deinstitutionalized. In December 2018, exactly 2,811 people with mental illness were waiting for entry to nursing and care homes. There are also waiting lists for other social services (Figure 1). Unfortunately, newly established supported housing is very rare. These services are rather provided in close connection to the process of deinstitutionalization and are still connected to the institutional service provision. This carries
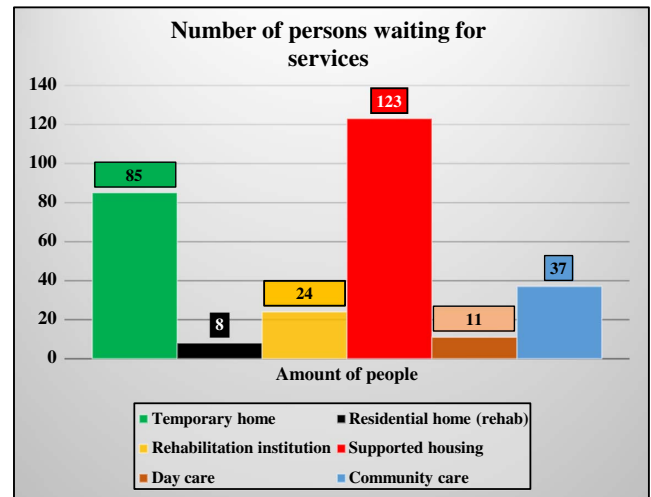

Figure 1. Source: Hungarian Social Users Registry, Hungarian Social Services Registry, December 13, 2018

the risk that the institutional approach for mental patients would be preserved, with the only difference being that the new institutions are smaller. The patients' lifestyle would not differ substantially from that in large institutional structures: the fixed operation of the majority without personal goals and individual responsibilities. The heritage of the nursing and care institutions still prevails, in conflict with the principles of the *recovery model* [11].

DISCUSSION

Stigmatization as a social phenomenon hindering deinstitutionalization

Social acceptance of people living with mental disorders in Hungary is well below that of other European states or overseas countries. Professionals working with these patients are not free from prejudices, either. To the question whether they would work in a psychiatric department after finishing their studies, 58% of the interviewed medical students answered straight "no," according to a survey carried out among BSc nursing students before the onset of their psychiatric clinical training [12]. This response is indicative of a significant change that has taken place in the perception and assessment of psychiatry during the past few centuries, a tendency that seems to have increased during the past decades.

However, the perception of psychiatric treatment is still not free from inconsistencies. Conflicts seem to originate in the open question of how mental disorders should be approached. The biomedical approach regards mental disorders as bodily illnesses, whereas the psychological approach regards them as originating in the psyche and not to be treated by medications, at least primarily. Sociologists view mental disorders in sociological terms [13]. Society's aversion originates in a false notion associating mental disorders with aggressive and violent behavior. Lacking adequate explanation, this aversion seems to stem from the fear of incomprehensible, often bizarre, human behaviors.

Aversion, mixed with fear and helplessness in the face of the unfamiliar, is the factor that prompts people to turn away and stigmatize those living with mental disorders. In his book "Shunned," Graham Thornicroft characterizes stigma by three components: causes connected to the lack of knowledge (ignorance), causes associated with attitude (prejudices), and behavioral causes (i.e., discrimination) [14]. Often pretentious and inflammatory, media coverage of the perceived or real violent acts of people suffering from psychiatric problems also plays an important role in shaping the social environment. Excessive public discourse and summary statements on the given events also have the capacity to influence public opinions unfavorably, further strengthening the stigmatization phenomenon.

The reality is that common social beliefs about mental disorders make patients struggle to find employment, make friends, and become full members of their communities. It is duly reflected in public responses to the possibility that a community will be chosen as a site to place deinstitutionalized mental patients. The moving of mental patients to supported housing is often preceded by residential protests, the collection of signatures, the submission of petitions, and other acts aimed to a certain degree at making political capital. Beside ordinary embarrassments, all actors in the deinstitutionalization process are exposed to stigmatization, not just the mental patients, but also their helpers. The stigmatization of mental patients becomes obvious to those who attend them. Experience has shown that it is more comfortable for professional guardians to make decisions for their clients, labeling them indecisive or helpless, despite the fact that seeking their views and consideration of their opinions is legal obligations [15].

Good practices in Europe

Following the work of Franco Basaglia in 1978, large psychiatric institutions for patients with chronic illnesses have been closed in Italy and converted to community care, and the social and health care of mental patients were reorganized according to individual needs. The supply of services for mental patients is provided by social cooperatives. The system is characterized by community solidarity and support [16].

In Lille, there has been a comprehensive reform of health and social care for mental illness over the course of 30 years. The mental health delivery system of Lille Metropole France is an excellent example of a fully integrated mental health and social service system. Lille's community-integrated mental health care is a feature of the most advanced 21st century, humanistic psychiatry [17].

In Denmark, the Recovery Program made new and significant demands on the way social services were organized in the city of Aarhus, as well as on staff qualifications. The program Activities of Recovery involves a redesign of services to focus on recovery. The activities include an initial evaluation, the draft of a realistic action plan, psychiatric treatment, education, employment, and social initiatives, with a personal coordinator's support. Recovery has produced positive results in the quality of life of users and their satisfaction with social services. Based on its success,

the program has been embedded more widely across the directorate of social services [18].

In Spain, as a result of regional reform in 1993, a foundation (Andalusian Public Foundation for Social Integration of People with Mental Illness – FAISEM) was jointly funded by four government departments (Health, Social Affairs, Employment, and Economy and Finance) to provide social support services for people with severe mental disorders in the community. FAISEM manages a network that mainly includes residential facilities and occupational and vocational activities addressed to mental patients already in contact with local psychiatric services, with the aim of promoting social inclusion, citizenship, and recovery [19].

CONCLUSIONS

The effectiveness of social services and the quality of the social care system have considerably improved during the past decade in Hungary. Persons living with mental disorders have more and more opportunities and choices at their disposal. There is a continual transformation of the care system that was established in the middle of the 20th century. Perhaps it is fair to speak of a shift of paradigm in social services, in the wake of similar changes in the health care system. These two systems are supposed to provide mental patients with unified care, based on their statutory cooperation, but this process is still in its initial stage. One can sporadically find cooperation between social and health care providers, but services are ultimately provided by two separate systems, often in parallel with one another. Top decision makers in the social sector aim to foster changes, and there are a number of examples of good practices to be followed by other service providers in the institutional system. Any approach focusing on the recovery of patients within the frame of communal psychiatric services must be seen in a positive light.

The presence of mass institutions providing specialized care is, unfortunately, still common. The lack of manpower and the low education of employees in the field, alongside a paternalistic, institution-based approach, and the congestion of old, run-down buildings are not favorable to the prospect of rehabilitation and the reversibility of mental illnesses. Considering the large number of new patients waiting for admission, the resources at hand, and the surrounding social attitudes, the deinstitutionalization is destined to be a long and bumpy road. The aim of reducing the misperceptions and stigmas that are more and more prevalent in Hungarian society must be implemented with predesigned programs in small steps. The availability of services targeting recovery and covering the personal needs of new clients is of particularly important. The so-called "social diagnosis" to be announced probably in 2019 will greatly help this process. Recovery is a process that requires one complex and integrated care system instead of isolated social services. It has to be based on services capable of satisfying individual needs, and last but not least, on faith in recovery. An oft-quoted definition from Anthony [20] provides a great explanation of this process.

"*Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.*"

In Hungary, the social and health professionals can help clients to redefine their mental illness, to learn self-management, to develop a positive identity, and to reappraise the social roles in their own lives.

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