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Mental Healthcare Policy Reform in Turkey: A Qualitative Study on the Perspectives of Service User Groups

Türkiye'de Ruh Sağlığı Politikası Reformu: Kullanıcı Gruplarının Yaklaşımı Üzerine Nitel Bir Çalışma

M. Kardelen BİLİR USLU[1]

[1] Social Policy Institute for Graduate Studies in Social Science, Boğaziçi University,
mkardelenbilir@gmail.com,
ORCID: 0000-0001-8563-2303

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ÖZET

Türkiye'nin ruh sağlığı politikası, 2006'dan beri bir dönüşüm sürecinden geçmektedir. Bu değişimin temel amacı, toplum temelli ruh sağlığı hizmetlerinin kurulmasına öncelik vermek ve ülke çapında erişilebilir bir ruh sağlığı hizmet ağını kurmaktır. Bu çalışmanın temel amacı Türkiye'de ruh sağlığı politikası değişikliğinin siyasetini analiz etmekle birlikte bu süreçte kullanıcı gruplarının rolünü ve ruh sağlığı kullanıcı gruplarının bu dönüşüm hakkındaki görüşlerinin nitel analizini ortaya koymaktır. Bu bağlamda, 2018 yılının Nisan ve Haziran ayları arasında Ankara, İstanbul ve İzmir'de ruh sağlığı kullanıcı gruplarının temsilcileriyle yürütülen 13 adet derinlemesine yarı yapılandırılmış görüşmeler gerçekleştirilmiştir. Bu makale, bu politika değişikliğinin hastane-toplum dengeli bakım modeli halini aldığını ve toplum temelli ruh sağlığı hizmetlerinin ruh sağlığı hizmetlerinin kullanımını ve erişimini arttırdığını ortaya koymuştur. Öte yandan, toplum temelli ruh sağlığı hizmetlerinin, kullanıcıların iyileşme süreçlerine sadece tıbbi açıdan yaklaşımları nedeniyle katılımcılar tarafından sorgulandığını ve bu politika değişikliğinin, Türkiye'deki ruh sağlığı sistemine iyileşmeyi kolaylaştıracak, sadece tıbbi destek yoluyla değil aynı zamanda ruh sağlığı sorunları yaşayan bireyleri güçlendirecek sosyal destek yoluyla bütüncül bir bakış açısı getirmede yetersiz kaldığını göstermiştir.

Anahtar kelimeler: *Toplum temelli ruh sağlığı hizmetleri, ruh sağlığı politikası, kullanıcı grupları, sosyal hizmetler, sosyal destek*

ABSTRACT

The mental health policy of Turkey has been undergoing a transformation process since 2006. This change aims to prioritize the establishment of community-based mental health care services and to organize an accessible mental healthcare service network across the country. The principal aim is to analyze the politics of mental health policy change in Turkey and to understand the role of user groups in this process by a qualitative analysis of the views of mental health user groups on these transformations. In this context, semi-structured interviews were conducted with representatives (n = 13) of patient organizations based in Istanbul, Ankara, and İzmir. This article reveals that this policy change took the form of the balanced care model, and introducing community-based mental health care centers provided to increase the utilization of mental health care services. However, the services in community-based settings were questioned by the respondents because of their purely medical approach to users' recovery processes and this policy change falls short of introducing a holistic perspective to the Turkish mental health care system that would facilitate recovery not only through medical support but also through social support that would empower individuals living with mental health issues.

Keywords: *Community-based mental health services, mental health policy, user-groups, social services, social support*

INTRODUCTION

Mental health services have developed in the following time stages: the rise of asylums, the decline of these asylums and hospital-based mental health institutions, and the reform of mental health services (Thornicroft & Tansella, 2002; 2004). In these periods, the center of gravity of mental health services has gradually changed from hospitals to community-based mental health services, which has evolved from the institutional-based services because of a deinstitutionalization movement. We can define the term deinstitutionalization in mental health policy as the closing and downsizing of large psychiatric hospitals and introducing smaller mental health care centers in the community. In time, it transferred the mission of psychiatric hospitals to these local centers which offer prevention, diagnosis, and treatment services (Fakhoury & Priebe, 2007; Chow & Priebe, 2013; Thornicroft & Bebbington, 1989).

The need for qualified and sustainable mental health care services is a global issue. Turkey took an action towards community-based mental health services by introducing reform in 2006. The National Mental Health Policy (NMHP) document was prepared with the collaboration of the World Health Organization (WHO) and the Ministry of Health (MoH) as a guideline for improving the mental health policies of Turkey in 2006 (MoH, 2006). After this, the National Mental Health Action Plan was published in 2011 to establish a service network that is based on a user-centered and community-based mental health care service model throughout the country. The primary goal of these two policy papers is to prioritize community-based mental health care services in Turkey and to organize an accessible and balanced mental healthcare service network across the country (MoH, 2006; 2011). The deinstitutionalization of the Turkish mental health system that started in 2006 adopted the balanced care model and it has launched the community-based mental health centers Thornicroft & Tansella, 2002; 2004; 2013; Yılmaz, 2012).

2. THE TURKISH MENTAL HEALTHCARE SYSTEM

The key features of the mental health system in Turkey can be summarized in three points. First, there is a shortage of both the size of the mental health workforce and the physical capacity in Turkey. The system has nine public and three private psychiatric hospitals across the country, and it provides outpatient mental health services in 149 mental health centers to 32,307 active service users (Zengin & RUSİHAK, 2017: 169-170). The insufficient number of psychiatric beds for individuals who need long-term inpatient care and the insufficient number of forensic beds for convicted criminals living with mental health issues are two well-known problems in the physical capacity of mental health services. According to the National Mental Health Plan, the number of community-based mental health centers will reach 236 by 2023, and the number of psychiatric and forensic beds will be also regulated and increased (MoH, 2011: 65-70). Second, the mental health workforce and physical capacity of mental health care services in Turkey are insufficient and they are lower than those in OECD countries (OECD, 2014). The mental health specialists in the country practice mainly in public hospitals in Ankara, Istanbul, and Izmir. Third, the establishment of preventive and primary health care services and integrating mental health and primary care includes preventive policies for people with mental illness, their families, and society. However, the mental health system in Turkey is based on psychiatric-based mental health services rather than preventive mental health services. The reform does not completely succeed in building related social services with a human rights-based approach and it does not facilitate strong independent living (Yılmaz & Bilir, 2020).

Four core actors have assessed from different points of view the policy of deinstitutionalization as follows: the state, private-sector, mental healthcare professionals, and user-groups (Piat, 1992; Rochefort, 1997; Lauber et.al., 2004; Speed, 2006; Sercu & Bracke, 2016). There has a growing interest in the transformation of Turkish mental healthcare policies from historical backgrounds to ongoing implications of the 2006 reform (Coşkun, 1987; Gökalp, 2002; Münir et al., 2004; Yazıcı et al., 2007; Dole, 2015; Bilge et al., 2016; Muijen & McCulloch, 2019; Bilir & Artvinli, 2021; Yılmaz & Bilir, 2020); but they have not considered the perspectives of user groups as the primary focus. However, with the growing role of user groups, the demands of patients for mental health policies and psychiatric care units have been taken into consideration by governments (Caria, 2009; Rose et al., 2016). In former studies, it shows that community-based mental health services require both organizational changes of the place where mental health services are presented and holistic reforms in other non-health-related fields, including social workers (Yılmaz, 2012; Yılmaz & Bilir, 2020). In this context, this article analyses the views of user groups on this policy change and it aims to contribute to the existing literature on the analysis of deinstitutionalization reforms from a user-based perspective.

3. MATERIALS AND METHOD

This study is based on qualitative methods to explore service users' experiences of the mental health care system in Turkey. In line with the conceptualization of Guest et al. (2006), there were primarily on 13 face-to-face, semi-structured in-depth interviews conducted with representatives who had a mental health issue, those with a family member who was living with a mental health issue, and those who are with human rights advocacy expertise in the mental health field between April and June 2018.

Two inclusion criteria were used to form the purposeful sampling method: first, most of the members of the organizations must be service users, and second, service users manage these organizations. The principal aim was to have direct access to representatives of service user groups known as peer support groups and grassroots associations at national, regional, and local levels. The author listed 13 service user groups to include in this study and made an appointment by phone. Seven of the 13 respondents were service users of the Turkish mental health system and they made up most of the representatives of service users. Only three of the respondents were primary caregivers with users in their nuclear family, and also, three had human rights advocacy expertise in the mental health area and they continue to represent their organizations. Table 1 shows the characteristics of respondents.

Table 1. Characteristics of the respondents

ID	Location	Gender	Respondent characteristic
G1	İstanbul	Male	Primary caregiver
G2	İstanbul	Male	Service user
G3	İstanbul	Female	Service user
G4	İstanbul	Male	Service user
G5	İstanbul	Female	Human rights advocate
G6	İstanbul	Female	Primary caregiver
G7	İstanbul	Female	Human rights advocate
G8	İstanbul	Female	Service user
G9	İstanbul	Female	Service user
G10	İzmir	Female	Human rights advocate
G11	İstanbul	Male	Service user
G12	İstanbul	Male	Service user
G13	Ankara	Female	Primary caregiver

The interviews lasted an average of 60 minutes and were conducted in Turkish. They were audio-recorded with the respondents' consent, the names of all respondents were anonymized, and then transcribed verbatim. The interview transcripts were analyzed in Turkish, the author translated from Turkish into English, and then she specified the participants' responses into patterns. The author classified the responses by categorizing and codes to associate themes and sub-themes. The responses got through the interviews were analyzed by thematic content analysis with an inductive approach (Braun & Clarke, 2008).

Transcribed data were coded in three steps. First, the coding was based on the experiences of the respondents in the mental health hospital and community-based mental health centers. Thus, it was involved that the respondents were encountered with the reforms made in the name of deinstitutionalization in the mental health system. The second step of the coding traced the patterns of social support mechanisms which should be provided in the community-based services. Third, the coding was focused on the representation of service users and their caregivers because the involvement of service users and their caregivers in health care came to the fore to reshape the mental health care services.

Secondary data sources, i.e. official statistical data and reports of global organizations, ministries, and NGOs, and comprehensive desk research were also used to get an overview. The views of these participants, both as people affected by these changes and as actors in the reform process, are crucial for a better understanding of the mental health policy changes.

The findings of this study have some limitations. First, family activists, mental health professionals, and human rights advocates found mostly the service user organizations; however, service users were incorporated into administrative bodies. It established only one of them in this study as a peer support group that was led by a group of users, while another one became a service user group organization because of a non-governmental organizations (NGOs) project. Second, this study remained limited to metropolitan cities. However, there are few associations in regions where there are psychiatric hospitals: Adana, Elazığ, Manisa, and Samsun, and the views of the participants may differ in different cities of Turkey. Third, the vast majority of existing service user groups are diagnosis-specific groups, most of which are related to schizophrenia; hence, this situation less reflected the experiences of service users with different mental illnesses.

4. RESULTS

The analysis included three broad inter-related themes: the lack of awareness about deinstitutionalization, the lack of social support mechanisms (tackling stigmatization; employment support; regular income support, and housing support); and the role of user groups in the Turkish mental health system.

4.1 The Lack of Awareness About Deinstitutionalization

With the NMHP and the National Mental Health Action Plan, a significant policy change started in the Turkish mental health system. During these developments, some common terms in the present study, including deinstitutionalization, community-based mental health model, and balanced care, were placed at the top of the policy agenda. Despite the increased use of these terms by the Ministry, mental health professional associations, non-governmental organizations, and user groups, there is not a commonly accepted definition of deinstitutionalization. In the interviews, while some participants had a general opinion on what deinstitutionalization is and how deinstitutionalization should be implemented, most of them did not have full knowledge of this field. As one respondent expressed that:

“Firstly, I want to say, you are using the concept of deinstitutionalization, we are also using it, we are talking like a concept that everyone seems to use. But, it is not. When we go to the Community-Based Mental Health Center (Toplum Ruh Sağlığı Merkezi in Turkish) training, we are talking about “deinstitutionalization” which is a concept that they have heard for the first time.” (G5, Istanbul, female, human rights advocate)

Although deinstitutionalization refers to decreasing the number of beds in psychiatric hospitals and to maintaining treatment in the community, some participants objected to reducing the number of psychiatric beds in Turkey.

“Why do I not agree (with the policy of reducing beds)? I think that the policies that are actualized will vary according to the conditions of the country. When talking about 600,000-700,000 individuals who have already been diagnosed, 10% of the mental health hospital beds should be protected, no

matter what the number of beds. We can call them expanded community-based mental health centers." (G1, Istanbul, male, primary caregiver)

The definition and content are ambiguous of deinstitutionalization. Respondents, however identified deinstitutionalization with the newly opened community-based mental health care centers. During the reform process, community mental health services has been expanded towards halfway homes, sheltered homes, day hospitals, other tertiary prevention and rehabilitation facilities, and sheltered workplaces. These services include preventive mental health care and programs, psychosocial treatments, follow-up, and treatment of the users in the community after the completion of the acute treatment in the hospital. The Ministry of Health principally operated these services, except sheltered workplaces. However, the lack of mental health workforce makes up a tough obstacle for the establishment of the planned team in the instruction. These centers distinguish themselves from hospital-based services by providing rehabilitation, work, and occupational therapies and workshops. One participant describes these centers:

"There are hobby areas, wood painting workshops and sports activities. There is an area where people can sit and drink tea and they can have a conversation." (G3, Istanbul, female, service user)

"I think it is going well; I am looking positively. Why do you ask? I am telling you because I lived in Bakırköy Psychiatric Hospital between 1994 and 2006. I went to Erenköy Psychiatric Hospital and the Alcohol and Drug Addiction Treatment Centers (AMATEM), and we passed into a very troubled period. But now I can give my blood, take my drugs within half an hour in my health care center. I have a psychologist and a psychiatrist who can explain myself when I am feeling stressed. It is a enormous blessing for me." (G4, Istanbul, male, service user)

The development of community-based care for users is related to a shift in the psychiatric discourse over time—from a biomedical model to the mentality of shared responsibility and social networks among different stakeholders. In our case, the transition of Turkey's mental health institution is open to debate in terms of whether it can provide services in a community setting. Respondents who are more familiar with the term deinstitutionalization say that existing mental health centers have continued to serve in a hospital-based service mentality rather than a community-based one. For instance,

"You called 40 or 50 people to the community-based centers. My friend says that he left the association and he went to the community-based center. I ask why and he says that I am covered by the state security. He does not have a guarantee; he takes half of his mother's monthly pension, and he lives alone. He says that when he goes to a place and has a guarantee. Maybe, he does not have too much money; he needs to eat in there. It is also a humiliation; you need to eat, then there are psychologists, psychiatrists, nurses who are making money, but they do not work. It is not deinstitutionalization. It may seem good to collect us and educate us there, but the content is also very important. Do you reach your goal? Can you cure him? Can you give him a job, a girlfriend, a marriage? These are very important." (G2, Istanbul, male, user)

As emphasized above, it does not evaluate the transformative power of community care as enough in this fieldwork. The participants mentioned the services are not adequate for them in terms of both quality and quantity.

An analysis of the interviews showed that the term “deinstitutionalization” evoked three issues in the minds of the participants: 1) discharging patients from mental health institutions; 2) decreasing the number of psychiatric beds, and 3) the opening of community-based mental health centers. All respondents shared their experiences and narratives on the practice of deinstitutionalization in the Turkish mental health system. While sharing their experiences, they compared their experiences with their previous experience with hospital-based services. Overall, respondents reported that their experiences with community-based mental health services have been more satisfying. The most emphasized point in the interviews has been the easing of access to mental health treatment, care, and medications with the establishment of a community-based model.

4.2 Service User Group Criticisms of The Lack of Social Support

Deinstitutionalization has the potential for the adaptation of the recovery movement. Rather than the traditional cure-oriented approach, the recovery movement has been defined as “a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and roles. It is a way of living a satisfying, hopeful, and contributing life, even with any limitations caused by illness” (Anthony, 1993).

The sufficient provision of community-based services undertakes a very important role in providing social support and enhance the recovery process for individuals with mental disorders in every aspect (Yılmaz, 2012). However, there are fundamental criticisms of user groups about the lack of social support mechanisms (1) tackling stigmatization; (2) employment support; (3) regular income support, and (4) housing support in the new mental health policy.

4.2.1 Stigmatization

As for the behaviour of stigmatization, the lack of knowledge about mental disorders is also similar across the world, regardless of differences between countries. There is a series of studies in different countries, including Germany, Greece, Poland, and Turkey. According to the Turkish studies, the 208 adults in a village near Manisa, Turkey thought that individuals living with schizophrenia are aggressive and should not be free in the community, and 61.5% of the sample did not want to be a neighbour of individuals living with schizophrenia, and 61.1% of the sample would not rent their homes to them (Sartorius & Schulze, 2005). One respondent shared his experiences of stigmatization.

“This society is ignorant about mental health. You have a big problem, but telling it to others is more than that. You are told that you are healthy in physical terms and you also have reasoning; so, you

do not want to work because you are lazy. You face these kinds of accusations. Yes, stigmatization also comes from the family and the social environment." (G12, Istanbul, male, user)

"My trouble started with stigmatization. Because I could find no one to talk to, I could tell no one that they addicted me to drugs and alcohol. For about a decade of my life, people offended me; I left myself alone. Nobody understood me, I already had a stigma; They labelled me as crazy. I was being used and stigmatized. I want them to treat us like human beings. Everyone may be in trouble like us. Everyone is a candidate for illness; so, I have been suffering for 24 years because I did not tell this." (G4, Istanbul, male, user)

4.2.2 Employment

It is a known fact that many people living with mental issues have more difficulty finding work and protecting their existing jobs than other people. Business affects mental health positively because it offers the use and control of skills, new opportunities, purposes, and economic resources. They also related it to having a respectable social position and personal contacts. Having a mental disorder is one obstacle to participation in the workforce across the world; and one cause of this situation is stigmatization. For example,

"It is not possible to find a job because of this illness. There are very well-qualified ones among them; they graduated from two universities, there are engineers, lawyers among them. Then they can only work if there are part-time jobs. There are too many problems. There were two reasons to open this café. One of them was to prove that schizophrenic patients could work, and the second one was to break the prejudice."(G13, Ankara, female, primary caregiver)

Employers are reluctant to hire people with mental illnesses. Most of the countries have legal orders to employ disabled workers; employers have to fill the disabled labour quota in their workplaces, but they remain reluctant (Thornicroft, 2006). Similarly, in Turkey's case, individuals who have mental issues are more disadvantaged than those with physical disabilities in recruitment. Our participants referred to their experiences to illustrate that persons with mental disabilities are more stigmatized than people living with physical disabilities in working life.

"There is already stigmatization in disability, but there is different stigmatization in mental health among the other disabled people. When there is a note of "mental disorder" in your report, he avoids you, he does not recruit you. Plus, there is a problem with guardianship related to your circumstances during the work. This problem is related to public opinion. If something will change, society has to do something." (G2, Istanbul, male, service user)

"Apart from that, there are common prejudices against our illness in society; we have to work on this issue. Some friends can find work opportunities. For example, they want to work; they are going to the workplace. They assessed us according to our disability status, so employers are asking what is your disability and he says that you have a psychiatric illness like schizophrenia, employers do not

hire him. They hire other handicapped persons, but the workplaces fear people with psychiatric disorders. There is such a disadvantage." (G11, Istanbul, male, user)

As stated above, there is a more negative attitude toward individuals with mental disorders, and it makes up an obstacle to their labour market participation and employment. One respondent emphasized it is also a common behaviour in the public sector.

Another obstacle to taking part in employment is associated with the insufficiency of vocational rehabilitation centers. These centers, as a part of community-based services, assist people with disabilities at the point of employment. Various services from these centers provide jobs and maintain employment for them. The focus group of vocational rehabilitation is the person who has a physical or mental impairment, and the primary goal is to break the barrier to employment. Starting from the 1960s, community-based mental health services were started with the opening of a day hospital, community mental health clinics, sheltered workshops, supervised work placement, and halfway homes. Occupational therapies, courses, and sheltered workshops were included in the treatment procedure. However, there was a decrease in community-based services during the 1990s (Yazıcı et al., 2007). As a part of the NHMP, it re-established these services in psychiatric hospitals in the 2000s. However, the respondent evaluated the function of vocational rehabilitation as quite insufficient. For example,

"The major problem is that we do not have a rehabilitation center after leaving the hospital. They (the service users) will be rehabilitated first and after the rehabilitation center, there is no vocational rehabilitation center. We do not have programs for their recruitment and placement.' '(G6, Istanbul, female, primary caregiver)

Despite the prejudices, the desire to work is higher among individuals with mental illness. For example, based on the research of people living with mental illnesses in Britain, while 52% of people with various disabilities responded that they wanted to work, this rate increase to 86% among people with mental illness, phobias, and/or panic disorders (Thornicroft, 2006: 57). Even if there is no statistical data on the thought of work among individuals with mental disorders in Turkey, the desire for labour market participation was also showed.

"Young people do not always have to go to these community-based mental health centers. Some of our friends do not want to work, but we also have friends who want to work. They need to provide workplaces and they need to help to socialize." (G11, Istanbul, male, user)

Discrimination towards the disabled people in the hiring process has explicitly prohibited by both the Turkish Constitution and the disability law. The law also makes a minimum employment requirement quota for the disabled people: public and private employers who have at least 50 employees must have three per cent of their employees must have a disability (The Republic of Turkey, 2005). The policy of sheltered workshops is used to create more employment positions for people living with mental health issues (The Republic of Turkey, 2013). Nevertheless, Yılmaz (2020) emphasizes that the sheltered workshops may cause segregation for those people in employment. The determination of discrimination and exclusion in employment can be seen in recruitment phase and employee' preferences. For instance, an official survey found that people with mental disorders that people living with mental issues are the least preferred group within the disabled people for employers (The Turkish Ministry of Family, Labour and Social Services (MFLSS), 2011). Two of the respondents proposed a collaboration between different stakeholders, i.e. employment agencies and community-based centers to create job opportunities for individuals living with mental issues.

"We are pleased with the functioning of the community-based centers. We are also pleased to say that these centers are fully working and supporting, but some young people are taking rehabilitation. These centers should have a protocol with the Turkish Employment Agency and the employment expectations of the members from these centers should be met. I am not mentioning lifelong rehabilitation." (G11, Istanbul, male, user)

4.2.3 Regular Income Support

Regular income support for people living with mental issues in Turkey can consider with the disabled pensions and home care support. The foundation of these supports dates back to 1976, with the approval of Law 2022, which provided a small monthly benefit payment for the elderly or the disabled poor. With the adoption of the Turkish Disability Act in 2005, an increase in disability pensions was regulated (The Republic of Turkey, 2005). They included the category of psychosocial disability in the Disability Act that was enacted in 2014.

According to the relevant articles of Law 2022, when people with disabilities over the age of 18 are in economic deprivation, they can benefit from a disability pension, a regular cash payment paid in three consecutive months. If the disabled person is under the age of 18, the family can undertake responsibility for him or her to benefit from the income support. However, they have to prove their disability by presenting a medical board report, which is given only by allowed health institutions. Disability has to be above 40%; They tied disability entitlements and pensions to this percentage in the medical report. Also, there are two additional criteria for entitlements to the disability category. First, the income level of the household must be below a determined level; second, there must be no close relatives who can undertake the financial responsibility for the disabled person (The Republic of Turkey, 2005). The most commonly used option as regular income support is the home care allowance. It is offered as a cash plan for care that falls below the official poverty line and is paid directly to the primary caregiver. More than half a million disabled caregivers are supported through this program. However, the distribution of the disabled people who receive this assistance to their subgroups is not known (Yılmaz & Bilir, 2020; MFLSS, 2020). In this research, they also criticized the eligibility criteria for the disability category. For instance,

"They diagnosed my daughter at an early age and she could hardly feel the economic strain in the economic sense. She was also a girl, but the parents were experiencing this financial distress. Now, the constitutional safeguard is valid until the age of 18. Who's going to look after my daughter after

*the age of 18? Let's say the family will take care of her. What kind of support did we give to the family? Now let's say that there is a very interesting thing about home care support; the monthly income of household members should not exceed two out of three of the minimum wage. 950 TL approximately 950 * 3 = 2,850 TL is enough for you. Let's say we do not give it anymore when it is 2,851 TL. Here, the relatives of the patient try to increase the number of residents in their homes. We are fooling each other on paper."* (G1, Istanbul, male, primary caregiver)

"They could be financially more supportive." (G3, Istanbul, female, user)

"They have financial troubles, and in fact; they are mostly tied to the hospital. It is also a big problem." (G5, Istanbul, female, human rights advocate)

At the point of medical board reports, there are also some critical issues. First, the percentage of the disability can vary among different health institutions; and the disabled person has to apply to over one hospital to take their medical board reports in this process. Second, the appointments for obtaining the health board reports are full-capacity; and new appointments are not be given in a short time. Third, they often limited the validity of this report to 2 years, and it is a recurrent process every 2 years. Two of the respondents also referred these three issues.

"In terms of families, there is a problem that gnaws at us about what will happen after us. That's also an enormous question mark. If the law is enforceable, it must be the law, otherwise writing something on paper means nothing to me. When a physically handicapped person retires, he or she can work according to the disability rate. There is no objection. However, our siblings who have schizophrenia cannot work when they are retired. The report can be renewed, and a schizophrenia patient 60 years old can be classified as recovered and his disability pension can be cut." (G1, Istanbul, male, primary caregiver)

As the respondents stated, people living with mental issues are tied to their legal guardianships because they do not have their source of income. They expect to take regular financial support to break their dependency.

4.2.4 Housing

Mental illness may also affect housing. Housing is a distinctive field where exclusion and discrimination can be observed more clearly. In the past century, we have seen that large mental health institutions served as long-term residences for people with mental disorders. With the policy of deinstitutionalization, it has transferred the role of these former institutions in housing to long-term home-care services in the community in different country settings. According to research, long-term home care provided in the community is less costly and is also preferred by most users. Community-based institutions offer a more qualified life than large, isolated hospitals (Thornicroft, 2006).

They constructed the role of the family as the primary caregiver with an attitude of protectiveness towards their family members, and they normally take full responsibility for them. It may recreate the dependency of individuals with mental disorders in their families. Community-based residential support is quite limited; It based the concept of residential support on "hope houses" that have been established across the country to provide community-based social care for people living with mental issues. Since 2016, 140 hope houses have opened as a part of community-based residential support across the country, and they reserved part of them for individuals living with mental issues. Although people living with mental issues prefer community-based facilities for housing and long-term care because of a better life compared to old mental health institutions (Thornicroft, 2006), the example of "hope houses" in the Turkish case was evaluated as restrictive.

"I had an experience with hope houses, which are halfway houses for people who are like us (people who have mental health illnesses and people who do not have economic power or family support). But, the managers of these hope houses managed our domestic life strictly." (G2, Istanbul, male, user)

The analysis of the user groups' representatives shows that most of these criticisms are related to the general socio-economic conditions of individuals with a mental disorder. Because the policy of deinstitutionalization has the potential to improve the quality of life of users, this study asked the participants about their problems, and their answers were mostly about mental health services, employment, housing, income, education, and stigmatization. While most of the participants had a positive impression of mental health centers, they also criticized the insufficient mental health and rehabilitation services, the mental health professionals, and the medical interventions. The lack of a policy aiming at tackling the social stigma was another criticism; the participants thought that individuals with mental disorders have been marginalized in society in terms of employment, education, and housing. Stigmatization arose basically from two points: distrust of individuals living with mental disorders and the tendency to distance them socially. Because of the effect of stigmatization, they reflected that they have been excluded from the labour market and have encountered discriminative attitudes in workplaces. We know that the Turkish family is excessively protective, but there is a weakening of traditional support mechanisms for providing income and housing. The problem of regular income and housing support for individuals with mental disorders are other criticisms made by most of the participants. The criticisms show that there are some prioritizations among user groups because they have suffered from the existing healthcare institutions, stigmatization, limited access to the labour market and regular income, and restricted housing support policies.

4.3 The Role of Service User Groups and Service User – Involvement

The role and power of user groups in Turkey's mental health system has increased over time; however, their effect has not still reached the expected level concerning the service users. It included the policy of strengthening user groups in the NHMP in 2006. It based this initiative on two points: to facilitate the work of non-governmental organizations' advocacy and human rights and to eliminate stigmatization and discrimination against service users and their caregivers (MoH, 2006). The non-governmental organizations have taken technical and financial support to be actively involved in the mental health system from the Ministry of Health. I asked it the respondents questions on the level of their involvement in political processes. Some of them showed their ongoing participation in various meetings about community-based mental health services. Two of the respondents took part in meetings that were conducted by different stakeholders, including ministries, international organizations, and provincial health directorates at both the national and the local levels.

"They invited me to meetings of the Ministry of Family and Social Policies and the World Bank. Those meetings were about the education of the professionals in primary care providers and community-based mental health centers. Representatives from WHO in Ankara came here (the office) and they liked us very much, so we also took part in their deinstitutionalization meetings."(G13, Ankara, female, primary caregiver)

"I talked to the officers from the Ministry of Health and the Ministry of Family and Social Policies. We met with some local groups, such as chief physicians, provincial health directorates, and municipalities."(G11, Istanbul, male, user)

It is also worth noting that even if the involvement of these user groups was not comprehensive; the participants thought their efforts contributed to the ongoing transformation of the mental health policies of Turkey at some points. One of them is about community-based mental health centers; the other one is about taking consent forms and records for electroconvulsive therapy. The Mental Disability Rights International (MDRI) report (2005) presented there was the use of electroconvulsive therapy (ECT) without anaesthesia in the six regional mental health hospitals; and it was a serious human right violation. For instance,

"I think it had a lot of influences. For example, there are mental health action plans and a patient council. They (the officers from the Ministry) were in the patient council. In 2006, we (the association) said that for the EKT (electroshock) to be done with an anaesthetic. The chief physicians were making meetings, and they invited us to one of them, so an interaction began. For example, the provincial health directorate called us to speak at least 3 times since 2009. They said that we are going to the balanced model and the community-based mental health centers were opened. I do not think that it's all ours, but I think it was sped up with this interactivity because there were a lot of different sources at the same time." (G7, Istanbul, female, human rights advocate)

"We reflected that there was no support other than medication, there was no salary, and no institutional support in the various meetings. We do not have mental health legislation. We expressed these issues in every press interview. These repetitions had taken into consideration. There has always been an interaction." (G11, Istanbul, male, user)

As a direct user involvement example from Turkey, a patient council was established because of a non-governmental project at Bakırköy Psychiatric Hospital, and service users have continued to gather every week. The council expresses the problems of individuals who stay in the hospital and submits its recommendations to the hospital management. The major goal is to take part in a decision-making mechanism in the hospital. One participant commented on the patient council:

"("From inside or outside? Everything opens up when you say that he is from me.". She explained in this way the activation of the patient council for 9 years and the concept of user involvement). They (the patient council) consisted of only patients and people who they knew, and they asked for themselves. Then, there is no resistance (in physicians and healthcare managers). This is very important, it is full user involvement. I saw afterward that there was such a mistake within associations. I was aware of this in the association; when I was in Bakırköy, I realized the dynamics came from working there. It's easy to criticize from the outside, so let's just say "I cannot do it." It is not the case, we should not evaluate the perception as a threat to her. When I say I want this for myself, we do not perceive it as a threat and I think it's a good thing." (G7, Istanbul, female, human rights advocate)

There were two points in the role's analysis of user groups in the Turkish mental health system: user involvement in policy processes and mental health care planning, treatment, and provision. The lack of representation of service users and their caregivers is a well-known characteristic of the Turkish mental health system; however, the role of user groups has increased in both the formulation of policy at a national level and service development at a local level. In this framework, some participants shared their political activities; they were involved in some policy-making processes at different levels by attending the meetings. It limited their scope to community-based mental health centers and services, medical interventions, psychiatric institutions, and mental health legislation. In terms of user involvement in mental health care planning, treatment, and provision, one participant gave as a positive example the patient council in Bakırköy Psychiatric Hospital. There should be more inclusive practices at the local level. The respondents who took part in policy processes emphasize the importance of their involvement in the ongoing transformation of the mental health policies of Turkey; however, they referred also to their concerns for the future.

5. CONCLUSION

The deinstitutionalization in the Turkish mental health system that started in 2006 took the form of the balanced care model, which was put into practice with the launch of community-based mental health care centers. Although most informants agree that this change eased access to mental health treatment, medications, and care, they suggest that the new model remained insufficient in other respects. It showed that the services in community-based settings were questioned by the respondents because of their purely medical approach to users' recovery processes. The vast majority of respondents suggested that the new model did not provide them with social support mechanisms in terms of anti-stigmatization, employment support, regular income support, and housing support.

This research also shows that the new model largely cannot support people with mental health issues to become autonomous individuals. Informants suggested that this failure is because of the following factors: the lack of regular income support and the problem of guardianship. It revealed that the eligibility criteria for income support schemes for people with disabilities are tight. These criteria include both a medical report showing disability and living under a specific income threshold. It showed that informants cannot benefit from income support schemes due to “recovery” being entered their medical board reports and/or their income level. The previous literature on the use of at-home care allowances for people with disabilities in need of social care in Turkey finds that this money has been mostly used to meet daily expenses of the family (Avşaroğlu, 2018), and it does not involve personal help or a personal budget system (Zengin & RUSİHAK, 2017). The respondents stated that people with mental health issues are expected to depend on their legal guardians or family members, which seriously limits their autonomy and hampers their full recovery.

Research participants also underlined the lack of community-based residential support as a limiting factor. Most informants lived with their parents. The social welfare system in Turkey expects that the family to be the primary caregiver that should undertake the entire responsibility for people with mental health issues. The situation of Turkey is like other Mediterranean societies where the protection of the family is dominant, as Thornicroft (2006) emphasized. The previous literature showed that people living with mental health illnesses prefer to live in community-based housing facilities because they are less costly and they have more autonomy over their lives compared to old mental health institutions (Thornicroft, 2006). “Hope houses” are the only alternative that people living with mental health issues have if they do not want to live with their families. But the capacity of this residential support is limited, and some respondents evaluated them as restrictive for service users.

It is laid stress on that social workers in the mental health system emerge as an identifiable professional group. They have made significant contributions to overcoming the current difficulties of the system and have taken an active role in combating the lack of social support mechanisms. They have different functions in the system, for instance advocacy, child protection, counselling and therapy, case management, resource allocation, social control services, organizing and empowering, managing, planning, and policymaking; and they have three key roles. In the first role, they related social factors to the emergence of mental illness, the course of illness, and treatment for mental illness; and social workers’ knowledge of social sciences is important as a counterforce to medicalization in mental health care. Their ability and awareness of community factors can be extremely valuable in facilitating the provision of services in the community. Second, social workers’ training on quality case management services and their multidisciplinary knowledge provides them an advantage over other professional groups in allocating resources, mobilizing resources, and coordinating services for the service users. Third, they can work with the families of the service users. It is highlighted that family members need professional help and they want to learn more information about the management techniques of mental illness, self-help groups and beneficial community resources for their family members and themselves. Social workers can guide and support them to better cope with the burden of care for their mentally ill family members (Aviram & Katan, 1991; Francoeur, 1997; Aviram, 2002; Carpenter et al. 2003; Oral & Tuncay, 2012). The number of social workers who are working in the field of mental health in Turkey has remained low and the institutional structure is limited. The knowledge, skills, legitimacy and effectiveness of social workers are also among those that need to be developed. These social workers should be committed to social work principles like human rights, empowerment, respect for differences, equitable access to services, advocacy and self-determination (Başer et al. 2013; Attepe-Özden, 2015; Bekiroğlu & Demiröz, 2020). Social workers should undertake their three key roles in the system for carrying out the lack of social support mechanisms (stigmatization; employment support; regular income support, and housing support) that were emphasized in this article.

It is expected that the policy change towards deinstitutionalization and community-based mental health care would bring positive improvements to both the quality of life of service users and the acknowledgment of the core principles of the recovery movement. To meet these expectations, the establishment of a community-based mental health care system requires an expanding service network with other support mechanisms, such as housing, financial support, anti-stigmatization legislation, and employment support. However, this article shows that this policy change falls short of introducing a holistic perspective to the Turkish mental health care system that would facilitate recovery not only through medical support but also through social support that would empower individuals living with mental health issues. User group representatives interviewed in this study report that stigmatization, limited access to the labour market and regular income, as well as restricted housing support undermines the success of the community-based mental health care model in Turkey. Finally, it shows that the role of user groups has increased in both formulations of policy at the national level, and the service development and provision at the local level. However, their representation in policymaking and service development and provision remains unsatisfactory. The analysis made here demonstrates the need for more inclusive policymaking and implementation in the Turkish mental health care system. The effective representation of user groups would provide valuable inputs for a holistic transformation in mental health care policy.

ETHICAL INFORMATION ON RESEARCH

Ethical approval for this study was obtained from the Institutional Review Board for Research in Social Sciences and Humanities of Boğaziçi University (No:2018 /13 Evaluation Date: March 14, 2018). Participants were informed in detail about the process and their rights, and verbal and written consent was obtained from them that they wanted to participate in the study voluntarily.

DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author.

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