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Challenges and perspectives of user-led initiatives in post-conflict and transitional communities: experiences from Bosnia and Herzegovina

Following the end of the war in Bosnia and Herzegovina (1992–1995), the process of reforming mental health services began, focusing on the development of community mental health centers as the backbone of deinstitutionalized care for individuals with mental health issues. During this period, several user associations were established with the aim of amplifying the voice of service users in shaping the conditions for their improved status and full participation in society. The aim of this paper was to analyse challenges and perspectives in the development of the user-led organizations and user-led initiatives in Bosnia and Herzegovina as a post-conflict and transitional community. The authors of this paper attempted to answer exactly how and to what extent post-conflict and transitional circumstances provide an opportunity for the development of the user-led initiatives. In searching for the answer, the case study method of a user-led organization with a twenty-five years experience was used. The findings show that in using opportunities and coping with challenges the key lies in the independence, mutual assistance skills, democratic management of the organization, involvement of all the users in the development and implementation of initiatives, openness to cooperation, inclusion in the social network and willingness to learn and share knowledge.

Key words: *mental health, deinstitutionalisation, stigma, user associations, community mental health.*

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Izzivi in perspektive uporabniško vodenih iniciativ v pokonfliktnih in tranzicijskih skupnostih: izkušnje iz Bosne in Hercegovine

Po koncu vojne v Bosni in Hercegovini (1992–1995) se je začel proces reformiranja služb za duševno zdravje, ki se je osredotočil na razvoj centrov za duševno zdravje v skupnosti kot hrbtenice dezinstitucionalizirane oskrbe za posameznike z duševnimi težavami. V tem obdobju je bilo ustanovljenih več uporabniških združenj, katerih cilj je bil okrepiti glas uporabnikov storitev pri oblikovanju razmer za izboljšanje njihovega položaja in polno sodelovanje v družbi. Cilj članka je analizirati izzive in perspektive pri razvoju uporabniško vodenih organizacij in pobud v Bosni in Hercegovini kot pokonfliktni in tranzicijski skupnosti. Avtorji poskušajo odgovoriti na vprašanji, kako in v kakšnem obsegu pokonfliktne in tranzicijske razmere ponujajo priložnost za razvoj uporabniško vodenih pobud. Pri iskanju odgovora je bila uporabljena metoda študije primera uporabniško vodene organizacije s 25-letnimi izkušnjami. Ugotovitve kažejo, da so ključni pri izkoriščanju priložnosti in spopadanju z izzivi neodvisnost, spretnosti medsebojne pomoči, demokratično upravljanje organizacije, vključevanju vseh uporabnikov v razvoj in izvajanje pobud, odprtost za sodelovanje, vključevanje v socialno mrežo ter pripravljenost za učenje in prenos znanja.

Ključne besede: *duševno zdravje, dezinstitucionaliazacija, stigma, uporabniška združenja, skupnostno duševno zdravje.*

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Introduction

Significant changes have been made in the field of the mental health care since the middle of the 20th century. In many countries, especially the highly developed ones, institutional care has been replaced by the community-oriented care with the development of new and alternative services, along with the strengthening of the user and recovery movements (Stein *et al.*, 2022). From passive recipients of mental health services, persons with mental health difficulties became active participants influencing mental health care policy and practice (Näslund *et al.*, 2023).

In these processes of change, the movement of users and user-led organizations played a significant role. Service users and user-led organizations have made an effort in democratization of the public policies and services, especially healthcare and social policies and services, with a tendency to make changes in receiving those services that would be in accordance with their rights and needs (Beresford, 2020). Also, new discoveries on mental health based on users' life experience contributed to focusing more on involvement and empowerment of users with the change of the focus of activities to the needs and wants expressed by the individual, and not on the symptoms or disability (Näslund *et al.*, 2023; Slade, 2009).

User-led organizations play an important role in the promotion of and advocating for the user-services involvement in the shaping of public policies and mental health services in accordance with the needs of persons with mental health difficulties (Rose *et al.*, 2016). Despite the fact that the involvement of the service users is emphasized in strategies, plans and declarations in many countries (Storm and Edwards, 2013) and that in the recovery-oriented approach the involvement of users is one of the key aspects (Slade *et al.*, 2014), and that there is a growing interest in the user-involvement concept (Thornicroft and Tansella, 2005), in practice it is not often achieved and sometimes it remains at a purely symbolic level (Laitila *et al.*, 2018).

In the implementation of the user-involvement concept, there is a huge gap between the developed countries and low- and middle-income countries. For example, while in British mental health services the concept of "user involvement" is embedded in service policy (Rose *et al.*, 2016), it is either a completely foreign or a not well-known concept in low- and middle-income countries (Lempp *et al.*, 2018; Ryan *et al.*, 2019). Socio-political and economic context in which persons with mental difficulties live significantly determine the organization, scope, provision and availability of the mental health services (World Health Organization, 2025; Kirkbride *et al.*, 2024) including the possibilities of inclusion and participation of users and user organizations in public policies and services (World Health Organization and Calouste Gulbenkian Foundation, 2014; Lempp *et al.*, 2018; Montenegro, 2018).

There is little research dealing with user involvement in low- and middle-income countries (Ryan *et al.*, 2019; Lempp *et al.*, 2018). Ryan *et al.* (2019) found that in the published research results from low- and middle-income countries, none of the research was led by users, and service users in these research projects were mostly the research subjects.

The aim of this paper was to analyse challenges and perspectives in the development of the user-led organizations and user-led initiatives in Bosnia and Herzegovina as a post-conflict and transitional community. The introductory part of the paper presents the post-war context of Bosnia and Herzegovina, the reform process of mental health services and the establishment of user associations.

Socio-political context of mental health system reform in Bosnia and Herzegovina

With the dissolution of the Socialist Federal Republic of Yugoslavia, the Republic of Bosnia and Herzegovina declared independence in March 1992. Shortly after gaining independence, the country was engulfed in a brutal and devastating war, which ended in late 1995 with the signing of the Dayton Peace Agreement. This agreement defined the current state of Bosnia and Herzegovina and its internal administrative structure, which is based on ethnic principles (Fočo, 2001; Gavrić *et al.*, 2013). Administratively, the state consists of two entities, the Federation of Bosnia and Herzegovina (federation of ten administrative units designated as cantons), and Republika Srpska, as well as one administrative unit with special status, the Brčko District of Bosnia and Herzegovina. These entities and the District are highly autonomous and maintain their own governance systems.

Following the establishment of peace, the country entered a process of transition, largely initiated and shaped by the international community. With the aim of establishing and maintaining peace, building a democratic society with a market economy, and moving away from a socialist governance model, a very complex and dysfunctional political system has been constructed to date – one characterized by intricate governance structures, decision-making processes, and economic mechanisms (Blagovčanin and Divjak, 2015).

A dysfunctional political system, a society deeply divided both politically and economically, a corrupt and fragmented state bureaucracy, unemployment, poverty, and the collapse of the education system are just some of the features of society that contribute to its entrapment in the past, the risk of renewed conflict, and the intensification of feelings of insecurity and helplessness (Blagovčanin, 2024). On the other hand, the war has resulted in numerous and long-term consequences for individuals, their families, and communities (Gavrić *et al.*, 2013; Kučukalić *et al.*, 2005; Priebe *et al.*, 2010).

Mental health system reform

Prior to the outbreak of war (1992–1995) against Bosnia and Herzegovina, the entire psychiatric care system in the country was primarily based on psychiatric institutions, but it did contain a minor focus on rehabilitation and resocialization of persons with mental disorders (Kučukalić *et al.*, 2005). During the war, the system for protecting persons with mental health conditions was completely devastated. As a matter of fact, the position of persons with mental difficulties during the war in the country and immediately after the war remains an untold story.

In Bosnia and Herzegovina before the war, there were four large psychiatric hospitals (Jagomir, Domanovici, Jakeš, Sokolac) for a long-term accommodation of persons with mental difficulties. In the beginning of the war, psychiatric hospital Domanovići near Mostar and Jagomir near Sarajevo were completely destroyed by continuous bombing. Patients from the Jagomir hospital were transferred to a completely inadequate kindergaden facility situated in a part of Sarajevo that was under siege throughout the war. It is alleged that a number of patients went missing during the transfer, but the number of missing patients is unknown. Also, patients from the Domanovići hospital were transferred to the premises of the Clinical Hospital in Mostar that could not meet their needs. Maslov, Babić and Klarić (2003) state that during the war, among the patients with schizophrenia, a greater number of suicides were caused by their relocation, inadequate accomodation and lack of food and medicines.

Also, in the beginning of the war, Hospital Jakeš near Modriča (a psychiatric colony) with about 1000 patients experienced severe war actions. Many patients were exposed to bombing, hunger, the lack of medicines and care (Radovanović *et al.*, 1994). This forced the staff to evacuate in the very beginning of the war a number of patients to Hungary (about 57 patients), the Psychiatric Clinic in Tuzla (168 patients) and the Popovača Psychiatric Hospital in Croatia (around 30 patients with severe mental disorders who were physically endangered) (Tešić and Golub, 2008; Avdibegović *et al.*, 1992).

In a post-conflict and ethnically highly divided country, a reform of the mental health care system was initiated in 1996 (Federal Ministry of Health, Federation of Bosnia and Herzegovina, 2012). Despite ethnic divisions and the difficulty of reaching consensus among ethnonationalist parties on almost any issue, the projects and programs of mental health system reform received support from all sides. Mental health care appeared to act as an integrative factor within a deeply politically and economically divided society. The reform goals seemed promising, especially in the early years when the education process involved a wide range of professionals, mental health service users, and their families.

A working group of experts was formed in both entities of Bosnia and Herzegovina, consisting of psychiatrists, psychologists, social workers, nurses and public health physicians, with the primary task of developing a training program for staff of mental health centers, psychiatric hospitals and primary health care, with the possibility of participation of non-governmental organizations, users of psychiatric services and their families. The plan and program of the education made by the expert group was approved by the ministries of health in both entities in the country.

The educational programs were realized with the support of World Health Organization, Swedish Psychiatric, Social and Rehabilitation Project for Bosnia and Herzegovina, HealthNet International, Medecins Sans Frontieres-Belgium, and Caritas Denmark-Danish Mobile Hospital. Training programs were implemented throughout the country in the form of training courses, short-term seminars, supervision, postgraduate and undergraduate training in the period from 1997 to 2001. The goal was to train staff of mental health centers, psychiatric institutions, primary health care and social work centers in providing care for people with mental disabilities in the community through introduction to the concept of community mental health, multidisciplinary and team approach, human rights-based approach, and involvement of users and their families.

In the training program other topics were included such as: trauma and working with the traumatized, how to cope with mental health problems in the primary health care, managing psychosocial problems, mental health of children and adolescents etc. Trainings were led by local and foreign experts, among others there were experts from Ljubljana (Vito Flaker, Andrej Kastelic and Darja Zavišek), Belgium (Anselm Derese, Myriam Deveugle, Roland Rogiers), the Netherlands (Guus Van de Veer), Italy (Mario Reali, Rocco M. Canosa), Sweden (Majda Omerov, Lars Jacobson, Bengt Lagerkvist, Ljiljana Kaleb) and others such as Robert Hayward and Peter Fleischmann (United Kingdom) who led trainings for the development of self-help and advocacy.

Alongside these educational programs, 38 community mental health centers were established and equipped (Cerić *et al*., 2001; Lagerkvist *et al.*, 2013). Strategies and policies for mental health were developed, the role of community mental health centers was defined, operational standards were established, and laws for the protection of persons with mental disorders were adopted – representing a very significant step toward improving conditions of care for people with psychological difficulties (Sinanović *et al.*, 2009). Improving the conditions of care have been reflected, for example, in better availability and a wider range of mental health services such as coordinated care, occupational therapy, counseling, and other forms of psychosocial assistance. The care for persons with mental difficulties was no longer solely relying on the psychiatrist.

Legal acts and policies make it possible for other experts to be involved in care and support, such as psychologists, social workers, social pedagogues, speech therapists, occupational therapists and others. The multidisciplinary teams of community mental health centers were in the local community, at the level of primary health care, which facilitated access and availability. Furthermore, admission and accommodation in the psychiatric institutions, as well as the use of coercion were legally regulated, which has resulted in a reduction in the number of days of hospital treatment and the use of coercive methods. The transition from hospital treatment to community care is facilitated through discharge planning policies and procedures and the creation of a post-hospital treatment plan.

For the first time it has been regulated that the user of the services is an active participant in the planning of admission, care and discharge. A particularly significant segment in the improvement of the conditions of care and the active participation of the service users was the introduction of the coordinated care based on the recovery and human rights. It all contributed to making the persons with mental difficulties to be more visible not only within the sector of the health care but also within other sectors within the community.

This reform process in the mental health sector was strongly financially supported by the international community (Lagerkvist *et al.*, 2013; de Vries and Klazinga, 2006). From 1996 until 2023, continuous efforts were made to strengthen the newly established system. A fundamental change in the context of psychiatric service provision entailed the limited use of psychiatric hospital beds, the opening of a network of community mental health centers, development of other community-based services, a multidisciplinary approach and teamwork, and the establishment of intersectoral cooperation (Čerkez and Avdibegović, 2017, p. 308; Maglajlić *et al.*, 2022).

In the policy and strategy of mental health, in both entities in BiH, the leading goal was to ensure care in the community for people with mental difficulties with an approach focused on recovery and human rights (Federal Ministry of Health, Federation of Bosnia and Herzegovina, 2012; Ministry of Health and Social Welfare of the Republic of Srpska, 2020). After all activities aimed at decentralizing and strengthening community-based mental health care—strongly supported by international organizations—the question arises: where do we stand today in relation to deinstitutionalization, which was one of the reform goals?

From the idea of deinstitutionalization to transinstitutionalization

The policy of deinstitutionalization in psychiatry is oriented toward transforming care practices by shifting away from institutional settings toward the provision of community-based care. Within this policy agenda, psychiatric deinstitutionalization has involved the closure or downsizing of large psychiatric hospitals and the development of comprehensive community mental health services with the goal of promoting social inclusion and the participation of individuals living with mental illness (Montenegro *et al.*, 2023).

Following this agenda, and considering the post-war context, efforts in Bosnia and Herzegovina were meant to focus on the construction and development of comprehensive community mental health services, while also working to improve conditions and reduce the number of beds in the only two psychiatric institutions that survived the war (in the entity of Republika Srpska: the

Sokolac Psychiatric Hospital and the Jakeš Psychiatric Hospital). From the very beginning of the reform processes, the principle of comprehensiveness was jeopardized by fragmentation – both in relation to different sectors of care, and fragmentation induced by war-related divisions and destruction.

On the one hand, various legal frameworks insist on a unified, continuous, coherent, and decentralized system of care; on the other hand, other norms and regulations restrict this and render the health and social care systems fragmented and disconnected. Portacolone *et al.* (2015), writing about the model of deinstitutionalization in Trieste, note that the restoration of citizenship in the broadest sense of the term (the right to life and participation in community social life, the right to housing, establishment of social cooperatives, participation in unions, political parties, religious and civic organizations, and the right to be mentally different) was central to the process of deinstitutionalization.

The foundation for this restoration was the creation of a "life project" through dialogue between service providers and users of mental health services. "Life projects" are developed to provide structure and inspire meaning in the lives of those seeking mental health services. Furthermore, they emphasize that through the "life project," attention shifts from symptoms and mere survival to long-term social integration of the individual, and to changing the position of the service user from a state of passive dependency to a state of active and engaged participation (Portacolone *et al.*, 2015).

In Bosnia and Herzegovina, over the past 27 years of reform, precisely this creation of a "life project" (Portacolone *et al.*, 2015) has been missing. Thus, despite everything achieved during these reforms, we are still faced with the fact that institutional care for people with mental disorders has not been stopped – on the contrary, it shows a growing tendency. As the number of psychiatric hospital beds and the length of inpatient stays have decreased, the number of beds in social care institutions and the duration of stays in those institutions have increased.

The growing trend of institutionalization of people with mental disorders in social institutions can be illustrated with data from the Agency for Statistics of Bosnia and Herzegovina. In 2018, a total of 1,144 adults with mental disorders were placed in social care institutions, while in 2023, that number was 1,473 (Agency for Statistics of Bosnia and Herzegovina, 2024). In comparison with data from the 2003–2008 period, we can see that in 2003, there were 519 such persons placed, and in 2008, the number was 562 (Agency for Statistics of Bosnia and Herzegovina, 2010).

Social welfare institutions, which were originally designed primarily for the care of individuals with intellectual disabilities, have in practice reoriented toward providing institutional care for individuals with mental disabilities. Research conducted by Šarić and Buljubašić (2020) indicated that there is a growing number of institutions in which a large number of users resides, that there is a transinstitutionalization of users and that the required conditions were not meet, which are primarily related to the creation of appropriate services and support for users in the local community after leaving the institution.

User associations in Bosnia and Herzegovina

During the initial period of mental health reform, user associations began to be founded. These associations brought together former psychiatric patients and people who lived with mental difficulties. The formation of user associations was supported by the staff of mental health centers and international organizations that supported mental health reform in Bosnia and Herzegovina, such as HealthNet International and SWEBiH. In 1999 and 2000, the first two associations were founded: “Vita” in Sarajevo and “Feniks” in Tuzla. The members of these associations chose to identify themselves as users of mental health services. In the following period, several more associations were formed, such as “Behar” in Mostar, “Stella” in Zenica, “Nada” in Doboj, “Sonata” in Trebinje, and “Novi Pogledi” in Gračanica. These associations were mostly affiliated with newly established mental health centers. The “Vita” association in Sarajevo was not closely tied to a healthcare institution; it was partly supported by HealthNet International, which managed part of the psychiatric institution reform project (Avdibegović *et al.*, 2003, p. 46).

In 2002, the user associations came together and established the Federation of Associations for Mutual Assistance in Mental Distress in Bosnia and Herzegovina. This Federation was supported by the Hamlet Trust through various projects, notably the “Pathways to Policy – involving users to create change” initiative, which aimed to empower users to influence local policy and practice and to connect them with other organizations within Hamlet Trust’s network (The Hamlet Trust, n.d.1).

However, this Federation, like the first user associations (with the exception of “Feniks” and “Sonata”), did not survive the internal crises within the organizations and the Federation itself, ceasing operations around 2005. The challenges faced by users – such as securing space for activities, freedom to choose activities, financial support, and independence from healthcare authorities – were considerable, particularly given the weak internal cohesion and organization among users. The dissolution of the Federation and some user associations coincided with the end of generous international support for the reform process.

Following the decision of the Swiss government to provide financial backing for a multi-year mental health project in Bosnia and Herzegovina (Placella, 2019), users and user associations regained the attention of various actors involved in the project. During the implementation of the Mental Health Project in Bosnia and Herzegovina (2010–2023), users of mental health services and their organizations were engaged to varying degrees and with diverse project goals. During this time, several user organizations were formed within community mental health centers, and continuous education was provided in the fields of human rights, advocacy, public speaking, employment, and the fight against stigma (Institute for Population and Development, n.d.).

Methods

In this paper, through the case study of the user association “Feniks” from Tuzla, we have analyzed the challenges and perspectives of the development of user-led organizations and user-led initiatives in post-conflict and transitional circumstances and attempted to answer the question to what extent and how do these circumstances provide an opportunity for the development of user associations? In selecting the case study of the User Association for Mutual Aid in Mental Distress “Feniks” from Tuzla, the leading criteria were the establishment of the association in the first five post-war years, continuity of work, management of the association by the users and autonomy of the association.

The criteria of the association’s autonomy referred to the association’s self-reliance and independence in relation to mental health centers, psychiatric hospitals, centers for social work and other social protection institutions. In relation to the criteria of the period of establishment of the association and continuity of work, of the seven user associations in BiH that were founded in the first five years after the war, only the association “Feniks” from Tuzla and the association “Sonata” from Trebinje still exist and continue to work today. The association “Sonata” from Trebinje, from the beginning of its foundation until today, has been led by experts in mental health who are also employees in the mental health services.

Given that the association “Feniks” has been run exclusively by users since its establishment, and given that it is autonomous in its work, and that it has a continuity of 25 years of work, we have analysed the challenges and perspectives of the development of user-led initiatives in a post-conflict and transition context through the presentation of the work of this association. The association’s documentation has been used in our research, such as narrative annual reports on the association’s work, reports on project activities, internal newsletters and other archived photos and written documentation.

Through the development story of the Association for Mutual Assistance in Mental Distress “Feniks” from Tuzla, we will attempt to show how one might face such challenges and view obstacles as opportunities for further strengthening and growth.

Challenges and perspectives of a user-led initiative – the story of “Feniks”

Several patients of the Day Hospital of the Psychiatric Clinic at the University Clinical Center Tuzla, who had years of experience living with mental illness and long-term psychiatric hospitalization, discussed during group therapy how they would like to have self-help groups that they could run themselves. The idea was discussed at length, steps toward its realization were considered, and in parallel, the hospital staff began educating patients about self-help and mutual support.

Over time, the number of interested patients grew, and within the group, the idea emerged to form an association, symbolically named "Feniks" (Udruženje za uzajemnu pomoć u duševnoj nevolji "Feniks", n.d.). One member immediately created a logo, while others engaged in exploring how to register the association. In 2000, they held the founding assembly in the premises of the Day Hospital and received approval from hospital management to base the association on hospital grounds. A room was made available to them to use.

However, they soon faced the challenge that the room could not be used freely; their entry, stay, and departure times had to be recorded. This was one of their first challenges. They had an association, but not the freedom to use their time within it as they saw fit. This led them to reach out to the local community and city administration. Through HealthNet International, they connected with Robert Hayward of The Hamlet Trust (UK) and Igor Šprajcer from "Altra" in Slovenia. Their visit brought valuable insights into how to operate independently from a health institution.

Continued communication with the city administration yielded results: the city provided space in the center, away from the hospital. Due to war-related damage, the premises were in ruins. With local community support, renovation was carried out with help from the adult prison administration in Tuzla. Prisoners and association members jointly renovated the space. One year after its founding, "Feniks" moved into the new premises. Now they could come and go as they pleased, engage in preferred activities, and use items like glass cups, bottles, cutlery, scissors – items banned in psychiatric settings. They assumed responsibility for themselves and each other. Mutual trust emerged. They felt human – like everyone else. This was a good example of a joint action, freedom of action and creativity derived from a strengths-based approach to helping. In this approach, individuals and groups who need support or who have difficulties are considered to have the capacity and abilities within their social network to achieve the necessary change (Folgheraiter and Rainer, 2017).

Following this significant initial success, new challenges arose. Operating required funds, thus raising the question of financial sustainability. The members had no prior experience or skills in fundraising. Professional supporters encouraged them to tackle problems independently, with backing only if insurmountable obstacles emerged. One activity requiring no funds was media engagement – though it demanded courage. Initially, members appeared in the media accompanied by Day Hospital staff. Eventually, they presented independently. With a local radio production company, they hosted a weekly show led by a member. They fought stigma and promoted mental health through media and direct contact with journalists – without funding.

This empowered them. They began lobbying to improve their status, particularly access to treatment. At the time, medications required co-payment, leading many to discontinue treatment and face relapse or rehospitalization. Informed by professionals that health laws exempted them from co-payment, they campaigned and lobbied politicians. They were heard in the Tuzla Canton Assembly and gained favorable outcomes.

After three years operating without financial support, the association faced a crisis. Membership dwindled – some lacked travel funds, others wished for refreshments or excursions. At one point, only three members remained, one of whom used the premises for sleeping. Their persistence and renewed cooperation with The Hamlet Trust and other associations in Bosnia and Herzegovina helped them survive. A Hamlet Trust-supported research project on users' status in Tuzla Canton gave them new motivation. Former and new members returned, enabling training, networking, and fundraising skill development.

They accepted various tasks – landscaping parks, street cleaning, rehabilitating returnee areas and cemeteries. Through such work, they earned enough to purchase a van, gardening tools, woodworking machines, and equip carpentry and art workshops. They began organizing excursions throughout Bosnia and Herzegovina. Although they did not speak English, they accepted training invitations abroad and relied on participants from former Yugoslav republics for translation. During this period, they learned to use computers, underwent IT training, and received their first computers. Throughout, "Feniks" strengthened its self-help group work.

A pivotal resource was Prof. Tanja Lamovec's book *Psychosocial Assistance in Mental Crisis* (Lamovec, 2005), which she generously allowed "Feniks" to translate and publish in Bosnian. This helped them understand how to develop user associations, organize and maintain self-help groups, advocate, combat stigma and discrimination, and fight for human rights. Ideas and practical advice on institutional crisis coping as provided by Professor Lamovec guided "Feniks" members in overcoming obstacles.

A second major milestone was reached in 2007, when the City of Tuzla granted "Feniks" the use of a house for the duration of 30 years. This house remains their base of operations. Distancing themselves physically and symbolically from psychiatric institutions and professionals was a significant challenge and bold step. It aimed to demonstrate that people with mental illness, with minimal support, are capable of responsibility for themselves and others and can contribute to societal change. The benefits – both individual and social – are significant. For example, several "Feniks" members, previously hospitalized for over a decade, through meaningful engagement with "Feniks," became key local actors in combating stigma and discrimination. The way that they did it was through sharing personal experience and knowledge of living with mental disorders, providing peer support, leading groups for self-help, activism and working on strengthening user assotiations.

Besides the aforementioned, it is significant to mention a user-led initiative in the field of research. The first user-initiated and conducted research on the needs and the quality of life of persons with mental disabilities in Tuzla Canton was conducted in 2003. This research was supported by The Hamlet Trust organization, which initiated in Bosnia and Herzegovina a Pathways to Policy programme (The Hamlet Trust, n.d.2; Maglajlić Holiček and Baldwin, 2009, pp. 68–69). This study was conducted on a sample of 319 users from the Tuzla Canton. The results of this study showed that 47% of persons with mental health difficulties receive very low monthly social benefits which could not cover even the food costs. Out of the 319 respondents, only 4% were in full-time employment, while 87% of them stated that they have very little social life and they go out rarely, and 63% were dissatisfied with the support they received from local health services (The Hamlet Trust, n.d.2). The key issues faced by the participants included poverty, unemployment, loneliness, lack of social status, and dissatisfaction with local health and social services (Maglajlić Holiček and Baldwin, 2009, pp. 68–69).

The results provided a foundation for developing further goals of the association, particularly concerning the improvement of the social status of persons with mental health conditions, enhancing access to health and social care services, and reducing stigma and discrimination – especially in the area of employment. The study also served as a starting point for subsequent research, focusing on topics such as access to mental health services, user satisfaction, employment opportunities for people with mental health conditions, and the specific needs of women experiencing psychosocial difficulties.

The results of a still unpublished study on the specific needs of women with an experience of psychosocial difficulties conducted in 2023 on a sample of 60 women with an average age of 40, indicate that the needs and the quality of life are similar to the results of the study conducted by "Feniks" 20 years earlier. Namely, 36.7% of women in this study are married, 50% of them live with their parents and are dependent on the parental help, 53.3% have below-average monthly earnings, 16.6% of them have their legal capacity deprived, and 29.4% mentioned an experience of abuse by a family member.

It is interesting that only 20% of women with psychosocial difficulties believe that they can independently manage their money and decide on with whom and where to live. Most women (70%) state that they need help in leading their lives independently, 51.7% need assistance in job search, 63.3% need support in relation to family relationships, while 58.3% have a need for safe housing.

In conducting this research as well as previous research, the users faced a number of obstacles and challenges such as: 1) How to reach research participants or the target group; 2) How to establish partnerships with health and social services; 3) How to make research findings visible to both the professional community and the general public; and 4) How to fund these activities. From experience, stigma and prejudice appear to be the primary obstacles in addressing these challenges.

Combating stigma

Anti-stigma activities were designated as a high priority. The initial initiatives included media appearances, including a weekly radio show hosted by a member of Feniks, as well as the marking of October 10 as World Mental Health Day. Feniks has continuously organized activities around October 10, involving other non-governmental organizations, the media, health and social workers, and educational institutions. Activities have included educational workshops in schools, a mental health parade, poster displays and brochure distribution with educational content, sharing personal recovery stories, producing short videos with anti-stigma messages, and engaging with health and social workers to address stigmatizing and discriminatory behavior.

From an initially member-led anti-stigma campaign without financial support, Feniks's campaign has grown into a sustained and financially supported effort. This was made possible through members' recognition of the importance of networking with other organizations and developing joint action strategies, alongside the recognition by local governing bodies of Feniks as a valuable partner in mental health promotion. Networking with other NGOs has, in itself, helped reduce stigma. Personal interactions between service users and the broader community play a crucial role in breaking down stereotypes and prejudices.

To illustrate this, we provide one example: Feniks was granted the use of a house by the city in a then-peripheral and underdeveloped urban neighborhood. The area around the house was unkempt, as was the street itself. Nevertheless, residents submitted a complaint to city and health authorities demanding that the "mental patients" be removed from their street, claiming that their children were now afraid to go to school. The request was denied. Members and friends of Feniks then undertook occupational activities to clean and beautify the house's yard, making it appealing to their nearest neighbor, who invited them to improve his yard as well. Soon, other neighbors began asking for help with yard work or various other tasks. Thus, contact was established. Stereotypes were broken. Over the following years, the street where Feniks's house was located became highly populated, with the Feniks house a recognized and welcomed part of it – its entrance proudly bearing the sign: "Life has no rerun."

Many people with mental disorders, such as schizophrenia, face symptoms and the consequences of their disorder on the one side, and on the other side stereotypes and prejudices stemming from misconceptions about mental illnesses on the other (Corrigan and Watson, 2002). Prejudice leads to discrimination and behavioral reactions that can be in the form of hostile behavior and harm, as stated in the previous example.

Stereotypes (negative beliefs), prejudice (agreement with beliefs and negative emotional reaction) and discrimination (behavioral response to prejudice) define stigma towards people with mental difficulties. The World

Health Organization (2001, p. 16) defined stigma as "a mark of shame, disgrace or disapproval that results in an individual being rejected, discriminated against and excluded from participating in a number of different areas of society." According to the World Health Organization (2001), social beliefs, attitudes and reactions determine many aspects of mental health care. Social environment is an important factor in recovery and integration of persons with mental difficulties.

Negative social environment reinforces stigma and discrimination. Generally, the social perception of mental health problems is dominated by negative stereotypes. People with mental health problems are often viewed through the prism of their health problems, regardless of their overall contribution to the society. Research suggests that the stigma of mental difficulties is a widespread and significant problem worldwide (Avdibegović and Hasanović, 2017).

Corrigan and Watson (2002) emphasize protest, education, and outreach as strategies for changing public stigma. They also state that stigma is further reduced when the general public encounters people with mental disorders who are able to keep jobs or live as good neighbors in the community. Interpersonal contact is further improved when the general public can regularly interact with people with mental difficulties as peers. In our previously described example, it was the direct interpersonal contact and good neighborly relations that contributed to changing the environment towards the members of the "Feniks" association and their integration into the local community.

The day center – a place for encounters and recovery work

Self-help groups, gardening, woodworking as a hobby, crafting jewelry and greeting cards, painting, shared coffee breaks, and occasional communal meal preparations formed the daily rhythm for users gathering at the Feniks house. There was a growing need to structure these activities and ensure their continuity and regularity. Occasional support from mental health professionals in the form of consultations was also needed. Students of pedagogy-psychology and social work participated as volunteers. New ideas emerged from this collaborative environment, offering solutions for improving the association's work and making it more open and attractive to new members.

It appeared that establishing a day center would be a good way to structure activities and ensure their continuity. The idea's implementation was jointly considered by users and volunteers and transformed into a small pilot project. The challenge was to identify who might support the idea – which donor, and with whom to discuss it?

In the local context, day centers fall under the category of social welfare services. For the social welfare system to provide financial support, certain conditions must be met – one of which is the employment of professional staff. A key problem was that Feniks had no employed professionals – in fact, no employees at all. So how could the association meet its own needs and integrate into the social welfare system while remaining independent from professional authority and maintaining its authenticity?

The question was how to remain true to oneself – open, honest, autonomous, and uninfluenced – preserving the founding idea of the association while also securing necessary support. The idea centered on encounters among individuals advocating for their personal and collective rights within the context of discrimination experienced due to mental health challenges.

While preserving this idea and being aware of the requirements for local government financial support, the first step toward realization was to pilot the day Center concept using donor funding in partnership with larger non-governmental organizations. Through this pilot project, the association was able to employ one professional, thereby fulfilling the primary requirement to receive financial support from local authorities for the day center. Sustaining this support involved annual reporting on fund use and submitting yearly requests for continued financing of day center activities.

Discussion

The mental health service user movement has been a key player in promoting user involvement in the development of services and a person-centered and recovery-oriented mental health care system in recent decades (Grim and Markström, 2024). Deinstitutionalization, questioning of the biomedical model of care and the legitimacy of biomedical theory, philosophical and political criticism of traditional psychiatry, and social changes created opportunities for the development of the concept of service user involvement (Millar *et al.*, 2016).

User-led organizations are groups or organizations led by the people who have a direct experience with a certain problem, situation, circumstances or difficulties. In the field of mental health, those are the people who have had or still have an experience with mental health difficulties. Those are groups or organizations established and led by the people who use their experiences as a basis for helping or supporting others. User-led organizations can be formal or informal groups that gather in order to provide mutual support or provide services that the public sector and other organization will not or cannot provide or to conduct trainings, disseminate knowledge, conduct research or activities for the promotion of mental health or campaigns for human rights and the fight against stigma.

User-led organizations, as non-profit organizations, have multiple purposes. First of all, their role is characterized by the goals of providing support to members (peer support, mutual aid activities, etc.), spreading knowledge and political advocacy, which includes influencing public opinion, politics and social development (Grim and Markström, 2024). These organizations are often small, underfunded and often struggle to survive. They often lack the contacts and visibility in the community to attract big names, launch media campaigns and attract the attention of decision makers (National Survivor Network, 2019).

In the post-conflict and transitional communities, the issue of mental health is often largely ignored by local authorities and the government of the country that is entering post-conflict reconstruction. In a large number of cases, support for the reconstruction of the country is provided by various international organizations and foundations for the purpose of rebuilding life in devastated communities such as Uganda, Afghanistan, Rwanda, Kosovo, Syria, Ukraine, etc. In the case of Bosnia and Herzegovina, various international actors participated in the reconstruction, which influenced the processes of physical reconstruction, economic and social recovery with financial and other resources.

Significant international support through various projects and programs was in the reform of mental health services. In the context of post-war reconstruction, the movement of users also developed, as we stated in the introduction. Contact and exchange of experiences with users from other parts of the world and organizations advocating changes in the policy of mental health care provided opportunities and gave a perspective to strengthen the local newly established user associations.

On the other hand, the collapsed social and health system, unsettled political conditions, fragmentation of society, poverty, unemployment, a large number of traumatized people, mistrust, stigmatization and other post-war circumstances represented significant obstacles. These were obstacles that had to be mastered every day in order to survive. Many of the user associations founded during the reconstruction period did not survive.

What made the “Feniks” association different from other user associations in Bosnia and Herzegovina and what helped them survive? First of all, it is the establishment of autonomy and independence in their work regarding the staff of mental health services, networking with similar organizations, openness to learning from the experience of other organizations, especially in the part of financing and developing the structure of the organization.

Furthermore, this group of people with mental health difficulties developed and nurtured mutual and peer support. The members acquired and developed the skills of providing peer support, first through mutual sharing of experiences and knowledge in dealing with mental health difficulties and everyday life problems. Later, they developed these skills through the exchange of experiences with other user organizations. They showed openness for meetings and enthusiasm in achieving their goals. Most of the members of this association drew their enthusiasm and strength from the experience of many years of psychiatric treatment. The activities were on a voluntary basis, and the association had no employees. In communication with the mental health services and decision-makers, they advocated, and still advocate, for the acceptance and recognition of their “experiential knowledge”.

The skill of leading the association was also important in the survival of the association, especially in the part of using the social network, strengthening the capacity of the association, in establishing partnership and cooperation.

Currently, the challenges the association is facing are how to harmonise its activities with what donors and policy makers expect from them, while remaining autonomous. Brown and Ormerod (2020) state that user-led organizations have more in common with their communities than with the statutory bodies or large non-governmental organizations providing mental health services. Understanding the specific roles that these organizations play in the field of mental health will include the representation of user-led organizations as a sector in mental health (Brown and Ormerod, 2020).

Conclusion

Post-conflict and transition communities in the process of reconstruction and reform simultaneously provide opportunities and are a source of numerous obstacles for the development of user-led organizations and user-led initiatives. In a way, the reconstruction of life in post-conflict communities can bring about new ideas, political changes and social actions that meet the needs of people with mental difficulties and other marginalized and socially excluded groups.

The role of international organizations in these changes is crucial, especially if support programs for the development of the mental health system are included in the provision of assistance for the economic recovery as well as physical reconstruction. Abandoning the traditional psychiatric approach in mental health care, developing and strengthening community-oriented services and a recovery-oriented approach, changing mental health policy can create an environment favorable for the development of user associations and initiatives.

Based on the experience of the user-led organizations presented in this paper, it seems important to emphasize that proactive organization building, independence, democracy in the management of the organization, openness to cooperation, inclusion in the social network, willingness to learn and share knowledge and experience are important factors in the development and survival of user-led organizations. These factors, as well as the involvement of all users in the organization’s decision-making and activities, were crucial in the realization of their initiatives.

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