Discursive exploitation or actual impact: Mental health anti-stigma campaigns in the post-communist area

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Summary

The post-Communist societies distinguish themselves by a high level of mental health stigma. Movements of mental health service users are weak and very often more oriented towards the provision of services and support for their members. They often lack capacity and resources to become actual shapers of the mental health policy, initiators and active participants of public discourse.

The paper presents the underlying situation of mental health care in the region, identifies and discusses peculiarities of local mental health anti-stigma campaigns and presents findings of the qualitative experts' research. The research covers eight post-Communist countries (Lithuania, Slovenia, Hungary, Croatia, Serbia, Romania, the Czech Republic, and Georgia). It reveals a twofold positive effect of mental health service users' activism, which has an individual therapeutic effect as well as helps fight stigma at societal level. In some post-Communist countries, such activism has failed to reveal its full potential due to lack of financial resources, widespread stigma and lack of mental health service users' leadership abilities.

mental health, anti-stigma campaign, service users, post-Communist

INTRODUCTION

In 2017 we happened to interview a mental health care service user activist with the aim of exploring current developments of the Lithuanian mental health care system. She emphasized the harm done by an anti-stigma campaign, which targeted stigmatizing attitudes of the employers. Part of the abovementioned campaign was a short video, which challenged widespread stereotyped reactions at the workplace when someone is experiencing the first episode of psychosis. The video was broadcasted on national television back in 2007. Ten years later, the video together with its main message was forgotten by the target group as well as by the general society. However, it still prevails in the narratives of users of mental health care services as a failure and offense, which hasn't helped fight stigma and, on the contrary, contributed to spreading and deepening it.

The scenario of the video was created by human rights and mental health non-governmental organization (hereafter NGO). The aim of this NGO is advocacy for human rights of persons with psychosocial disability, deinstitutionalization of psychiatric care, modernization and reform of the entire mental health care system in Lithuania and neighbouring countries of the for-

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mer Soviet Union. In the wide typology of stigma reduction strategies, the abovementioned campaign can be classified as a 'Protest' – formal objection to negative representations of people with mental illness or the nature of these illnesses [1,2].

The post-Communist region is characterized by a highly institutionalized system of psychiatric care, the predominant medical model of disability, and fragmented mental health policy [3-6]. It is distinguished by a high level of stigma, intolerance, and discrimination towards certain vulnerable groups of society, including persons with psychosocial disabilities. Movements of mental health care service users are weak and very often are more oriented towards provision of charity, services, and support for their members, instead of becoming influential shapers of the national mental health policy, initiators and active participants of the public discourse [7,8].

Such circumstances determine the ultimate necessity for anti-stigma campaigns fighting the existing prejudices and contributing to the inclusion of persons with psychosocial disabilities. On the other hand, a delicate question arises as to the rhetoric used in the formulation of the main message. This message needs to both challenge stigmatizing attitudes and provoke discussions, at the same time it has to be subtle and acceptable for persons with psychosocial disabilities.

Two researchers representing the academic sector and expertise by experience in the field of mental health have joined their forces to analyze mental health anti-stigma campaigns in the post-Communist region and identify their main patterns and characteristics. Objectives of the paper are as follows: to present the situation of mental health care in the region; to analyse peculiarities of main mental health anti-stigma campaigns; and to reveal the perspective of mental health service users on raising awareness and fighting stigma.

The results of the research reveal the unique perception of mental health service users about the need for anti-stigma campaigns as well as about their role planning, implementing and evaluating those campaigns. It will provide insights on intersections between the knowledge embodied in the authentic expertise of mental health service users and rhetoric employed by the anti-stigma campaigns. The research results will also contribute to the practice of user-led research and user-led design of anti-stigma campaigns.

Psychiatry in the communist world

Analysis of mental health anti-stigma campaigns in the post-Communist region is inseparable from understanding the specifics of the Communist psychiatry and its enduring influence upon mental health care systems in the region.

First of all, psychiatry in the Communist world is notorious for being a means of "systemic and pervasive" [9 p127] political abuse of the Communist regime. Researchers estimate that thousands of dissenters were hospitalized for political reasons: "a biographical dictionary published by IAPUP in 1990 listed 340 victims of political abuse of psychiatry as well as more than 250 psychiatrists involved in these practices. An investigative commission of Moscow psychiatrists, who researched the records of 5 prison psychiatric hospitals in Russia from 1994 to 1995, found approximately 2.000 cases in these hospitals alone" [10 p34].

Decades of widespread political abuse cannot be perceived as an ad hoc and random practice. It is a result of the holistic, well planned, scientifically and ideologically justified strategic approach. Bloch summarizes all the systemic constituents that resulted in the politicisation of the psychiatry: „the state's monopoly as sole employer, the centralised and rigid hierarchy inherent in the medical bureaucracy, the role of the Communist Party, especially at levels of authority, and the inculcation of Communist morality in the physician by political studies in his medical education, and by the oath he takes... provide fertile soil for the germination of nonmedical applications of psychiatry" [9 p128].

Stalin expected that the „New Soviet Psychiatry" inspired by works of I.P. Pavlov would contribute to the emergence of a „new, tame and self-sacrificing Homo Sovieticus" [11 p332]. Pavlovian psychiatry was biologically oriented and addressed the biological origins of mental illness. The main attention of scientists and practitioners was paid to genetic research and medicine-based treatment. The „New Soviet Psychia-

try" ignored and rejected the impact of the environment and social context, otherwise, it would not be possible to explain the emergence of such conditions as alcoholism, neurosis, and homosexuality in the socialist society [9 p129].

The diagnostic concept of "sluggish schizophrenia" developed by the Moscow School of Psychiatry conveniently widened the definition of schizophrenia. A unique scheme for the classification of this condition was introduced by its leader prof. A. Snezhevsky and his colleagues. Even the mildest behavioral change facilitated the application of this diagnosis especially to justify the involuntary confinement of the state's political enemies [9,10,12,13].

As a result, the diagnosis is made more liberal than in the Western countries: "schizophrenia was diagnosed much more frequently in Russia than in other countries, particularly in Moscow: the prevalence of schizophrenia in Moscow (5-7 per 1.000 population), is almost two times higher than in the U.K. (3-4 per 1.000)" [14 p435]. Psychiatrists dominated mental health: there were very few psychologists (5.000 all over the Soviet Union, in comparison to 37.337 psychiatrists in the year 1989) and no clinical social workers [15]. All tasks usually performed by social workers and psychologists were implemented by psychiatrists and nurses [15]. Moreover, the psychiatry in the Communist world penetrated other important spheres of public life. In addition to policy and national security, psychiatrists played an important role in education, social affairs, and penitentiary system. Domination of a strongly medical-oriented science of defectology resulted in placing too many children in the borderline category of those with disabilities [16 p9]. Children with disabilities were provided with services either in boarding schools or special care homes for those deemed uneducable [17]. Locking psychiatric patients for decades in psychiatric hospitals allegedly 'wiped off' from the surface of Communist society such social problems as disability and homelessness, unemployment and poverty. Researchers estimate that "approximately one-third of the dissidents in the 1970s and early 1980s being sent to a psychiatric hospital, rather than to a camp, prison or exile" (10 p42).

Manipulation with and misuse of psychiatric diagnosis, high institutionalization and over-medicalization of psychiatric care resulted in an overarching stigma associated with mental illness. There was neither political will nor means and measures to fight it. The discourse around psychiatry was highly politicized and concentrated in the hands of large and influential institutional actors, whereas an alternative public discourse was absent. The system prohibited any types of social activism by parents of children with disabilities, users of mental health services, self-help groups, who could potentially introduce alternative concepts of mental health care, require diversification of expertise, pluralization of approaches thus limiting the power of state institutions (17).

Post-Communist Psychiatry

Perestroika and the collapse of the Communist block changed many layers of society. However, the system of psychiatric care remained one of those pillars most resistant to change. Post-Communist countries started reforming systems of mental health care, first of all by passing the new laws on psychiatric care (e.g., in Russia, a "Law on Psychiatric Care and Guarantees of Citizen's Rights in its Provision" was introduced in January 1993, in Lithuania "The Law on Mental Health Care" in 1995, in Hungary "The Health Care Act" in 1997", "The Law of Georgia on Psychiatric care" in 2007). Modifications in legislation had only a limited impact and did not manage to alter the situation in mental health fundamentally. According to the report "Psychiatry as a tool for Coercion in Post-Communist Countries" [18 p14], "many of the mental health institutions remained inhuman environments and places where many human rights abuses were a daily occurrence, while the level of psychiatric care was far from acceptable and knowledge about modern therapeutic approaches, the role of relatives and carers and the self-help capabilities of mental health users remained scarce and limited".

The role of the psychiatry in the post-Communist societies has shrunk and lost its political, ideological and inter-sectoral domination. Yet psychiatric hospitals, as other institutions, that "employed abusive practices in the past find it hard to shake off their tainted reputations" [19

p2]. Directors of those establishments were inclined to preserve their political influence and for decades remained in the leading positions. The regionally widespread trend upholding the influence, premises, structure, and hierarchy of the former psychiatric and social care institutions implies keeping residues of the abusive Communist mental health care system.

Stigmatization of mental health care and widespread perception of people with psychosocial disabilities as unpredictable, aggressive and dangerous [20,21,19,22] resulted in shifting the role of psychiatry from politically authorized "guardian of ideology" to alleged "guardian of the society". Both roles require psychiatric institutions to control deviant behavior. Negative and stigmatizing picturing of persons with psychosocial disabilities in the public discourse creates an unfavorable climate for deinstitutionalization of psychiatric care and development of community based mental health care services. These circumstances also hinder the civil activism of mental health organizations and service users in the region.

Rebirth of civil activism

Policymakers do not perceive mental health as being amenable to defined, easily costed, readily understood and easily implemented solutions [23]. After the collapse of the Communist block, psychiatry had to adjust to the new circumstances, which included loss of its political power and influence, commitment for inter-sectoral and cross-disciplinary collaboration, modernization, decentralization, and shift from medical to bio-psycho-social paradigm. The success of these processes is associated with and largely depends upon the tangible involvement of non-governmental organizations, service users, informal carers and family members in the decision making. In mental health field service users' organizations are the main drivers of change while advocating for policy reform and development of community-based services, fighting stigma and discrimination. In Western democracies service users' movements emerged at the end of the 1960s and the beginning of the 1970s as a response of „anger against the biomedical model, psychiatry and institutions" [24 p209]. A mental health care service user is more than an individual with a unique personal psychiatric experience. 'Expert patient' [25,26], 'professional service user' [27], 'expert by experience' [28,29] are the concepts of individuals with lived psychiatric experience, which resulted in their expertise. These experts possess the potential for influence in many different areas of the mental health care system through lobbying, advocacy, media work, providing evidence and personal story for anti-stigma campaigns.

Mental health care service users' movement was one of many vectors of the civic activism that emerged after the collapse of the Communist block. The West believed in the crucial role of civil society building the democratic welfare states. Western democracies launched and funded extensive programs to promote empowerment, good governance and the development of non-governmental organizations in the region. This led to the development of a network of mental health and disability NGOs, which focused on the provision of services and filled in the gaps left by the state. They offered alternative frameworks of service delivery, including innovative, community based, human rights-oriented mental health care services.

However, there is still a lack of mental health care service users' and caregivers' self-organized activity in the post-Communist countries [19,20,33,31]. Moreover, those movements are fragmented and demonstrate different approaches: Holand [32 p19] identifies the existence of two 'somewhat separate subcultures within the disability NGO community in the region'. One of those subcultures consists of users of mental health care services. Users' organizations acknowledge the importance, yet rarely assume their own role fighting stigma, advocating for community-based services, shaping mental health care discourse and policy. Members of this community prefer to remain invisible to the general society and choose to operate in the 'safe' environment. They choose taking responsibility for publicly rather invisible activities, such as provision of psychosocial services or art therapy, distribution of charity, organization of self-help groups, thus solving immediate and short-term welfare needs of their community members. Petrea [4] explains this phenomenon as lack of trust, developed by survi-

vors of the totalitarian regime. Another reason is associated with stigma and fear being publicly exposed as users of mental health care services or members of a mental health NGO [33,34]. On the other hand, mental health advocacy is indivisible from constant visibility, active participation in the public discourse, sharing personal experience. There are some NGOs operating in the region on international level, implementing the twofold role of the think-tanks and advocacy for mental health reform. Members of those organizations are professional human rights lawyers, sociologists, social policy analysts, social workers or psychologists, whose focus on mental health is rather based on professional interest than on lived personal experience. In those organizations, users of mental health care services are involved on an ad hoc basis as lay experts, consultants or board members. They do not constitute a significant majority and perform a rather marginal, advisory role in shaping strategic goals of the advocacy organizations. Activities of these organizations are oriented towards long-term goals, including advocacy for mental health policy reform, promotion of human rights and fighting stigma. Visibility, publicity, active participation and social campaigning are important tools employed by those organizations while pursuing their goals.

Although working in the same mental health field and pursuing similar goals, both types of organizations experience 'some minor tension' [32 p19]: advocacy organizations are being perceived as acting too political; service provider organizations are criticized for being too soft in their instrumentalities and short-sighted in their strategic goals. In addition to ideological tensions, financial constraints are also important, since both types of organizations compete for the same scarce funding sources. Service user-led organizations are more successful in obtaining funding for small scale national or local projects, while advocacy organizations compete for funding of large international projects. Consecutively, types of funding and profiles of donors predispose the character of activities funded. International donors are interested in general, sustainable objectives, such as "building and sustaining a culture of human rights and of supporting the emergence of an independent civil society, (...), promoting political pluralism and democratic political representation (...) of members of marginalised and vulnerable groups" [35 pL77/85-89]. Though national and local donors formulate concrete 'orders', e.g., the Department for the Affairs of the Disabled under the Ministry of Social Security and Labor (Lithuania) identifies the priorities for NGO funding as follows: "social rehabilitation services for persons with disabilities in the community; support for disability associations; accessibility of the built environment; periodic publications for persons with disabilities; integration of persons with disabilities through sports; mobility for persons with physical disabilities" [36].

Advocacy organizations at their disposal have a larger amount of funding and a greater degree of freedom to implement a wide variety of measures of their own choice, such as monitoring human rights, developing and piloting alternative services, influencing policy and fighting stigma. User-led organizations lack such financial and decision making freedom and are often squeezed into the role of the service contractors.

RESEARCH

Expert interviews were chosen as a method of qualitative empirical research in order to explore knowledge in the field of user-led mental health and human rights activism in the post-Communist region. The focus was put on exploring expert knowledge, which is rooted in the activities of user-led mental health NGOs.

From the authors' point of view, it is the NGOs that have contributed most significantly to the reform of mental health care in the post-Communist countries. The focus was put on mental health service users-led NGO's because (1) worldwide they are recognized as an important driving force for changes in mental health policy; (2) they have unique on-the-ground personal experience.

The research took place in January – April 2019. Experts from the most influential national mental health care service user-led organizations from the post-Communist countries were interviewed. The initial list of potential participants of the research project was composed according to a set of criteria as follows: 1) practical in-field knowledge of the topic; 2) active partici-

pation in national user-led NGO activities; 3) activism on an international level.

The data were gathered for this article during nine interviews with experts, four females, and five males. The quotes from these interviews are assigned to LT (expert from Lithuania), RO (Romania), SI (Slovenia), GE (Georgia), HR (Croatia), CZ (Czech Republic), HU-1 and HU-2, 2 respondents (Hungary) and RS (Serbia). The professional backgrounds of the research participants are not specified, most of them have shared their personal histories of being a user of mental health care services.

A fixed set of questions was presented to the experts. Following methodological advice on expert research, semi-structured interviews were conducted in a flexible and open way [37]. Interviews were conducted either face-to-face or via the internet using Skype software due to significant geographical distances. Some experts preferred filling in the written form of the survey. Either English or Lithuanian languages were used. Interviews lasted from 20 to 50 minutes. Interviews were transcribed and coded with a focus on thematic units [38].

RESULTS

The experts were asked to rate the influence towards the mental health care policy of the following actors: user-led NGOs, advocacy think-tanks and representatives/insiders of the system (including politicians, officials, service providers). Each of the actors were asked to assign a certain percentage of influence, making 100% the total sum. Experts estimate that user-led organizations have the smallest amount of influence comprising only 9.38%. The highest assigned percentage of influence of user-led organizations composed 30%, the smallest was 0%. According to the experts, the advocacy think-tanks enjoy a much higher degree of influence (29.9%), while representatives of the system, according to the experts, possess the largest amount of influence (47.6%).
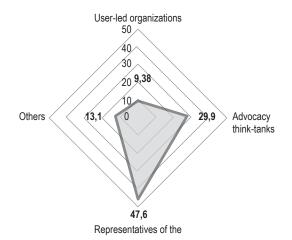

Fig 1. Influence of different stakeholders towards mental health care policy.

Proud identity

Goffman defines stigma as an attribute that is deeply discrediting. According to him, stigma reduces the bearer "from a whole and usual person to a tainted, discounted one" [39 p3]. The mental health stigma is especially fluid, it encompasses persons with a psychiatric diagnosis, their family members, mental health professionals, and psychiatric institutions. Moreover, it is a label that penetrates and spoils the very identity of its bearer [39].

Research findings reveal the shift from "spoiled" [39] to proud identity of mental health care service users, who become human rights activists, founders and/or active participants of user movements and organizations: "[we are] quite visible, integrated into disability movement, recognized by psychiatrists and family organization, as well as by the national organization of social workers" (GE). Stigmatizing identity provides a solid base for mobilization into user organizations [40]: "after being hospitalized for mania at 19 and then next year it took me 15 years to realize that I'm not the only one having bipolar mania. I found a description of an episode in a book [written by] a person I knew from before. I made contact with her, we became best friends and co-founded a micro organization" (SI).

Link and Phelan [41 p379] conceptualize stigma as a „persistent predicament", the negative consequences of which are so difficult to eradi-

cate. Research participants share their stories of 10-15 years of activism, which consequently led to recognition, respect, and tangible results. Successful activism is a result of acting at many levels: „I represent a local DPO (disabled persons' organization), I'm also one of the founders of the initiative group of women with disabilities, a board member of a local human rights NGO, plus a member of the National Prevention Mechanism visiting closed institutions" (GE); "we are members of EUFAMI [European Federation of Associations of Families of Persons with Mental Illness] since 2005" (LT).

The majority of experts have already overpowered stigma at a personal level. Open speeches of their psychiatric experience during public events, on radio and television is the most evident proof of it. A Romanian expert has defined it as a "power of a personal example". Six of them regularly appear in the popular public media with their personal stories or expert comments after high profile cases. According to the research conducted by Link and Cullen [42], contacts with persons with mental illness reduce fear of them. Research informants also believe it is the most effective stigma fighting measure: "every person who has opened up and has felt understood is a success story because every single small victory is another brick out of the wall of stigma" (CR). Moreover, it has been gaining popularity during the last years. Users of mental health services increasingly tend to openly speak about their experience: "a lot of people are willing to share their experiences on public events, in front of cameras, in the media. More now than in 2012 and we attribute this to our constant work on destigmatization through projects" (HR). Out of the nine countries, only a Lithuanian respondent could not mention any successful case of a personal story sharing: "there was this case from one small town when we tried to ask someone to publicly share [psychiatric experience]. Most often, people are afraid because of the stigmatization, they are not willing to be open and go public" (LT). Meanwhile, the Serbian peer had the courage to attend a TV show to discuss a criminal story involving alleged psychiatric diagnosis and publicly confront the widespread association of mental health and criminal behavior: "I'm glad I had a chance to stand against that irrational idea" (RS).

Anti-stigma campaigns: pro and contra

Small scale attempts to decrease stigma lead to small successes: "stigma is decreasing mostly thanks to focused projects of NGOs, public campaigns and great work done by patients 'associations" (SR). There is still a lack of initiatives and tangible results on the macro level. Therefore, respondents unanimously speak of frequent, latent and ongoing manifestations of stigma in their countries. Mostly they identify it on the national level: "stigmatization is still very noticeable in Croatia" (HR); "stigma is twice higher in Georgia than elsewhere" (GE). Such intuitive perceptions, based on respondents' personal experience correspond to trends identified by research: according to Rusch, Agenmayer, and Corrigan [43], public attitudes toward people with mental illness seem to have become more stigmatizing over the last decades.

Stigma leads to low self-esteem; it results in discrimination during interpersonal interactions, (un)intentionally restricted opportunities of persons with psychosocial disabilities [43,44,45]. Given the fluid and penetrating character of stigma, respondents state the necessity of a hybrid war against stigma, utilizing a combination of methods to achieve a palpable change: "fighting stigma should target persons with psychosocial disabilities to be aware of their rights; mental health service workers; carers of persons with psychosocial disabilities; related systems, such as education, social welfare, employment; politicians and decision-makers; and population at large" (RO).

Respondents name a wide variety of efforts to tackle stigma: "We fight on all possible levels" (HU-1). These efforts include seeking and nurturing collaboration with other sectors, including media, arts, and academia: "we organize peer support groups… produce documentary films and manuals online… organize art-drama workshops with Forum Theatre elements… produce a radio show… have a mobile psychosocial peer team… our members do lectures at the Study Center of Social Work" (HR). Every respondent stressed the importance of working with the media. News media is an important target for awareness-raising because, on the one hand it provides "overwhelmingly dramatic and distorted images of mental illness that em-

phasize dangerousness, criminality, and unpredictability", on the other hand, as scientists put it, news media "may also be an important ally in challenging public prejudices, initiating public debate, and projecting positive, human interest stories about people who live with mental illness" [46 p99].

Unfortunately, user-led NGOs don't have sufficient capacity, human and financial resources to implement large anti-stigma campaigns: "smaller campaigns being conducted include a small number of people, all because of the lack of time and resources needed for the maintenance of continuity" (HR). NGOs encounter difficulties getting funds even for their small scale initiatives: "We are contemplating a series of published personal accounts in a book but still trying to find a publisher and state funding" (SI).

The UN Convention on the Rights of Persons with Disabilities [47] explicitly emphasizes the need for State Parties to "raise awareness throughout society", and "combat stereotypes, prejudices and harmful practices relating to persons with disabilities". Among other awareness-raising measures, the State parties are encouraged to initiate and maintain effective public awareness campaigns. Nevertheless, the respondents' opinions significantly differ in terms of organizing a State-funded and implemented anti-stigma campaigns. Four respondents (Croatian, Serbian, Lithuanian and Georgian) support the idea of organizing them: "If a national scale campaign existed, we could look at it as effective on a bigger scale". The remaining five are rather against large public anti-stigma campaigns: "I don't believe having ever encountered an effective anti-stigma campaign" (HU-1) "I know only

state-managed anti-stigma campaigns which usually wind up with no real effect… I am very critical of government-financed campaigns promoting mental health… I cannot name a successful campaign…. Nothing really changed" (SI).

Notably, respondents emphasize two crucial aspects of large anti-stigma campaigns. First of all, they stress the importance of continuous and coherent efforts which might include but shouldn't be limited to the sole campaigns: "honestly, I do not believe in anti-stigma campaigns because a simple campaign cannot change mentalities and approaches towards persons with psychosocial disabilities. In my opinion, fighting stigma is a long process" (RO). Second, all of them accentuated the need for an actual involvement of either users of mental health care services or their organizations: "what is extremely important, users and helpers should appear together as equals" (HU-2).

Anti-stigma measures

Corrigan and Penn [48] divide strategies to diminish the impact of stigma into three paradigms: education, contact, and protest. Those strategies are later operationalized by Corrigan et al. [49] as follows: educational strategies include all types of sharing information for general public and targeted groups; interpersonal contacts comprise meeting and interacting with members of the stigmatized group and are likely to lessen the level of prejudice; social activism or protest highlights the injustices of various forms of stigma. Information on anti-stigma measures obtained from the experts is summarized in the table below.

Table 1. Types of anti-stigma measures per country.

Type of strategy	Countries/ measures	HU	HR	SI	RS	GE	RO	CZ	LT	Total
Education	Media work	x	x	x	x	x	x	x	x	8
	Education and training	x	x		x	x		x	x	6
	Public events		x	x	x			x	x	5
	Arts and culture		x	x		x		x		4
	Awareness raising	x	x		x		x	x	x	6
	Political advocacy						x	x	x	3

Contacts	Sharing personal story	x	x	x	x	x	x	x		7
Protest	Challenge, blockade or boycott									0
Underlying strategy	Research						x	x	x	3

The educational strategy is the most popular measure known for and implemented by respondents. It included such broad methods as media work (public reactions to stigmatizing media messages, special leaflets for journalists, media breakfast, etc.); education and training (trainings for helping professionals, spreading information in the general society, brochures and newsletters); organising public events (such as the World Mental Health day); diverse creative artistic measures, such as film festivals, theatres, exhibitions; awareness-raising campaigns, e.g., organising the Living Library, broadcasting videos.

The second strategy – sharing a personal story – is implemented in all but one country, by all but one respondent. As already mentioned, Lithuania forms an exception here and almost ignores this important anti-stigma method. Diverse international researches state that "meeting people with serious mental illness seems to do more to challenge stigma than educationally contrasting myths versus facts of mental illness" [49 p.967].

The strategy of protest is associated with unconventional actions, such as boycott, blockade, sit-in, or spreading messages criticizing and challenging stigmatizing attitudes and behavior. According to the research data, this strategy is absent among the participants of the research. There was no evidence of direct protest actions, implemented by the participants of the research or their organizations. Similarly, international research rarely examines protests or social activism concerning public stigma [49]. Moreover, these authors suggest that, according to their investigation, "protest is not a good strategy to affect stigmatizing attitudes and behavioral intentions" [49 p967]. Protest campaigns are publicly noticeable, nevertheless, they are associated with challenging and controversial visibility. First of all, such visibility fundamentally contradicts attempts to portray mental health service users as regular people. Secondly, such provocative measures would confirm the stigmatizing public perception about the unpredictable and vola-

tile nature of mental health service users. Hence, weighing the large price of controversial visibility mental health service users' organizations tend to focus on two remaining strategies.

Research as a basis for anti-stigma measures has been mentioned by only three experts. A Lithuanian expert mentioned research on stigmatizing attitudes towards persons with mental health problems among the population and disappointing results of it. The research data revealed the highest prevalence of stigma in the labor market. This information prompted more employment-oriented activities. Such research-informed practice is an outstanding example, although associated with financial restrictions, constantly faced by users' organizations.

CONCLUSIONS

The post-Communist region is a phenomenal area for mental health research because it contains the well-preserved recollections of the stagnant past, evidence of the turbulent present and allusions of future perspectives. The relics of the former system are still recognizable in the physical environment, public discourse, mental health policy, and professional practice. On the other hand, more or less successful mental health care reforms and discussions about the future of the system are taking place in each country. Mental health care service users are the immediate witnesses, beneficiaries, and shapers of those processes.

In some respects mental health care service users' activism in the post-Communist region echoed the trends in Western countries. Yet in the post-Communist region, these initiatives emerged, developed and evolved over a concentrated period of time. Given such circumstances, certain mental health activists have preserved the institutional and evolutionary memory of the paradigm change from its very beginning in the early 90s.

Mental health service users' activism has a twofold positive effect because it is both useful for their own personal healing, growth, and

self-realization as well as for fighting stigma at societal level. However, in some post-Communist countries such activism has failed to reveal its full potential due to lack of financial resources, widespread stigma and lack of leadership abilities.

This gap is partially filled in by the human rights and mental health advocacy organizations which have sufficient professional expertise and dispose of relatively larger financial resources. Nevertheless, their initiatives and advocacy campaigns insufficiently involve and reveal mental health care service users' perspectives. This leads to certain tensions between both types of organizations, while mental health care service users feel being manipulated, publicly stripped and exploited.

To avoid such tensions, rhetoric and practice of mental health care service user involvement should become a central component of mental health policy. Good practices of their involvement could include the following components: addressing stigma and discrimination in the society and among staff; participation in planning new and changing existing services; ensuring that involvement is neither declarative nor manipulative; addressing accessibility issues (especially important is informational accessibility); providing support, supervision and capacity building; monitoring and evaluation of involvement.

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