



## Cultural Contexts of Health and Well-being

Workshop report

Klecany, Czechia  
2–3 October 2017

# Culture and reform of mental health care in central and eastern Europe



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## ABSTRACT

The WHO Regional Office for Europe, the WHO Collaborating Centre on Culture and Health at the University of Exeter (United Kingdom) and the National Institute of Mental Health (Czechia) convened a workshop on culture and reform of mental health care in central and eastern Europe on 2–3 October 2017 in Klecany, Czechia. The aim of this workshop was to improve understanding of the key cultural aspects that impact and drive mental health care reform in the central and eastern European region. This report outlines the key points and recommendations made by participants in relation to this objective.

## KEYWORDS

MENTAL HEALTH SERVICES  
HEALTH CARE REFORM  
CULTURE

CULTURAL COMPETENCY  
HEALTH POLICY

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# Culture and reform of mental health care in central and eastern Europe



REGIONAL OFFICE FOR

**World Health  
Organization**  
**Europe**



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## Executive summary

The WHO Regional Office for Europe, the WHO Collaborating Centre on Culture and Health at the University of Exeter (United Kingdom) and the National Institute of Mental Health (Czechia) convened a workshop on culture and reform of mental health care in central and eastern Europe (CEE) on 2–3 October 2017 in Klecany, Czechia. The aim of this workshop was to improve understanding of the key cultural aspects that impact and drive mental health care reform in CEE.

The workshop was part of the WHO Regional Office for Europe's ongoing work to promote awareness of the relationship between culture and health. In 2015, under the umbrella of the European Health Information Initiative, the Regional Office launched a project on the cultural contexts of health to systematically investigate how cultural contexts affect health and health care in order to develop more effective and equitable policies. A result of this work has been the recognition that policy-making for health has much to gain from applying research from the humanities and social sciences.

To this end, the workshop's objectives were to:

1. establish and synthesize key cultural drivers of mental health care and its reform;
2. identify new potential research areas addressing cultural aspects of mental health care and its reform; and
3. recommend aspects of culture through which research and further understanding can influence policy and practice in CEE.

Workshop participants gave presentations that highlighted historical and cultural drivers of reform, examples of reform processes and lessons learned, and methodologies for examining culture as relevant to mental health care in the region. These presentations were followed by plenary and small-group discussions to further explore the issues raised by invited speakers. The group made solid progress across all objectives; in particular, it identified the following set of key cultural drivers of mental health care and its reform:



1. cultures of decision-making in service provision and the evaluation of decision-making processes;
2. cultures of collaboration among stakeholders, particularly the inclusion of service users and their families; and
3. cultural understandings of community-based care among various stakeholders.

Participants recommended methods and approaches from the humanities and social sciences to address these cultural drivers in CEE. They agreed that these could inform a more people-centred approach to reform by amplifying the voices of those with mental disorders and/or psychosocial disabilities, and by fostering communication among stakeholders at all levels. Such efforts towards inclusion and collaboration are vital to the development of effective and empowering mental health care systems across the region.

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## Introduction

The WHO Regional Office for Europe, the WHO Collaborating Centre on Culture and Health at the University of Exeter (United Kingdom) and the National Institute of Mental Health (Czechia) convened a workshop on culture and reform of mental in central and eastern Europe (CEE) on 2–3 October 2017 in Klecany, Czechia (see Annex 1 for the programme, including a list of speakers and their presentations). Participants consisted of 31 professionals in diverse fields (see Annex 2) from Armenia, Belarus, Czechia, Hungary, Latvia, Lithuania, Poland, Romania, the Russian Federation and Ukraine.

Recent years have shown increased recognition of the importance of culture across the continuum of health. The 2014 Lancet Commission on Culture and Health argued that “the systematic neglect of culture in health and health care is the single biggest barrier to the advancement of the highest standards of health worldwide” (1). Successfully implementing any high-level public-health or development strategy – including the 2030 Agenda for Sustainable Development (2), the European policy framework for health and well-being Health 2020 (3) and the European mental health action plan 2013–2020 (4) – is contingent on a better understanding of the intersections of culture, health and well-being. In response, the Regional Office initiated a project on the cultural contexts of health to systematically investigate how culture affects health and health care (5).

In the field of mental health, the importance of cultural contexts is particularly evident. These contexts shape the entire continuum of care, from people’s decisions to seek help in the first place to the types of help they seek, the social support they receive and the degree of discrimination they experience. Culture also shapes the kind of interactions that mental health professionals have with their clients, from providing a diagnosis to designing a treatment plan. Indeed, culture can be considered a driver of the very articulation of mental health itself, as perceptions of normal or abnormal responses and experiences are highly contingent on cultural contexts.

## Background

In recent decades, countries in CEE have experienced a range of transformations that have impacted significantly on understandings of and responses to mental health (6). The social and economic upheaval and cultural shifts of the post-socialist era have been linked to changes in the prevalence of mental ill health and addictive disorders (7). Concurrently, fundamental ideas relating to concepts of self, normativity, belonging and authority have been called into question. In this context, mental health professionals have had to reposition themselves to address a plethora of changes and challenges, including the reform of psychiatric services towards more community-based programmes, the rapid evolution of new psychological therapies and the influence of pharmaceutical companies.

Understanding the cultural contexts and drivers of mental health and mental health care is crucial as countries in CEE engage in reform. This reform commonly involves a shift from an institutional approach that applies segregation and exclusion to a patient-centred approach that focuses on equality, opportunity and inclusion. Developing a community-based system of care that embodies these principles is a core aspect of reform across CEE.

High-level support and resourcing are essential for such reform, but equally important are culturally nuanced understandings of service-user and carer experiences, needs and priorities (8). Thus, evidence-informed approaches to mental health should look not only to biomedicine and neuroscience, but also to more subjective, narrative forms of evidence derived from lived experience (5). Going forward, successful reform will be characterized by an emphasis on listening to and involving people with mental disorders and/or psychosocial disabilities throughout the process of change.

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## Aims and objectives

The workshop's scope and purpose covered the exploration of both negative and positive cultures of mental health – that is, factors that function as barriers to or enablers of reform. Its objectives were to:

1. establish and synthesize key cultural drivers of mental health care and its reform;
2. identify new potential research areas addressing cultural aspects of mental health care and its reform; and
3. recommend aspects of culture through which research and further understanding can influence policy and practice in CEE.

Participant presentations shed light on historical and cultural drivers of reform, highlighted examples of reform processes and lessons learned, and outlined methodologies for examining culture as relevant to mental health care reform in CEE. Presentations were followed by plenary and small-group discussions to further explore the issues raised by invited speakers.

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## Historical and cultural drivers of reform

This session aimed to identify key developments within the fields of psychiatry and psychotherapeutics; examine the changing concept and role of stigma in diagnosis, treatment and care; and explore how these understandings can be harnessed to provide care that affirms and supports the human rights of service users in the region. This provided a foundation for a discussion of the historical and cultural drivers of reform in CEE.

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### Key points

- The normative culture of institutionalized mental health care spans social, clinical and political realms.
- Mental health services and practitioner education are almost exclusively biological in their orientation, and social approaches to care are neglected.
- High levels of stigma and discrimination deter the disclosure of mental health problems and limit the acceptability of deinstitutionalizing mental health services.

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## Summary of interventions

Soviet-era perspectives and practices continue to influence psychiatry and psychotherapeutics in CEE. This era, characterized by rigidly centralized health care, left few opportunities for the participation of civil society, limited the rights of service users and hindered efforts to advocate for change (9,10). In some areas, socialist health care systems and so-called mental hygiene campaigns focused on prophylaxis, emphasizing the need to prevent mental illness for the good of the collective. This fostered fear of mental disorders and psychosocial disabilities, and perceptions of those who experienced them as unproductive members of society.

These and other stigmatizing concepts continue to inform regional policies and practices that systematically exclude service users from decision-making, planning and evaluation of care. Only recently have countries in CEE begun to discuss the concept of living positively in the community with a mental illness, and most mental health care systems have not yet undergone deinstitutionalization (see Box 1).

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### **Box 1. Mental health care reform in Lithuania**

In most former Soviet republics, mental health care systems are still highly institutionalized and biologically oriented. As Robert van Voren of the Human Rights in Mental Health – Federation Global Initiative on Psychiatry explained in his presentation, catching up to global standards after Soviet psychiatry's decades-long disconnection from developments in the field has required effort and time. In some countries, the Soviet psychiatric nomenklatura managed to maintain leadership positions and keep reformers at bay by using their close connections to the former communist leadership.

While many positive reform projects took place in the late 1990s and early 2000s, reform is now at a standstill and, in some cases, sliding backwards. Stigmatization is still pervasive, and mental illness is commonly met with fear or apprehension.

In Lithuania, for example, while today's quality of care greatly exceeds that of the Soviet era, community-based mental health services are still very limited in scope. As in almost all other former Soviet republics, the system of institutional care that isolates people with chronic mental illness or disability from society is still in place. Many young psychiatrists and other mental health professionals emigrate because of this unfavourable situation.

Corruption is also a reality, due in part to the very low salaries of mental health care professionals. Many juggle multiple jobs and fail to prioritize their poorly paid work in mental health institutions. As such, the quality of services remains low.

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## Summary of discussion

Participants discussed the fact that **highly institutionalized mental health services** have isolated people with mental disorders and/or psychosocial disabilities from society, but also from mental health professionals, who may only interact with service users during a brief diagnostic period. This systemic segregation has reinforced a cultural norm of institutionalization at community, clinical and political levels in CEE. In Belarus, for example, families of people with mental health issues often expect hospitals to take care of their relatives in order to protect their own reputation and status.

Despite the evidence base supporting the efficacy of multisectoral approaches to mental health care, community-based or outpatient services remain inadequate and **psychosocial (non-biological) services are often unavailable**. The pervasive medicalization of mental health issues contributes to this scarcity of alternative services, as does a lack of regulatory mechanisms for psychosocial interventions – for example, many countries in CEE lack a system of certification and licensing for therapists.

The **biological orientation of educational curricula** in many countries reinforces this barrier. Students lack contact with service users, and have little to no exposure to fields such as social science, economics or public health. Of particular concern is the lack of integration of clinical social workers, who could provide a bridge between the more biomedical interventions of psychiatrists and the social contexts of healthy integration and recovery.

The segregation-based structure of institutional care leads to the mystification of mental illness and **high levels of stigmatization**. Media coverage of extreme cases fuels stigmatization by generating fears of violence, in spite of the evidence that people with mental disorders and/or psychosocial disabilities are more likely to be victims, rather than perpetrators, of abuse.

Historically, this social construct was misused for political purposes: during the communist era, leaders used the label of mental illness to justify the removal of political dissidents from society for forced “treatment” in mental hospitals (11). At this time, hospitals also cast votes on behalf of their residents. Even today, the legal consequences of disclosing mental health problems, such as the loss of a drivers’

licence and restricted employment opportunities, perpetuate fears of the ramifications of help-seeking. This complicates service uptake, and contributes to the **large treatment gap** in the region.

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## Cultural aspects of mental health care reform

This session aimed to explore the range of cultural drivers that facilitate or hinder the successful implementation of reform in the region. It also examined what stakeholders mean by community-based care, and what its development requires within the broader social, economic, political and legal contexts of CEE.

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### Key points

- The perspectives of people with mental disorders and/or psychosocial disabilities have been missing from mental health services in the past and are now vital for reform.
- The development of community-based care models requires cross-sectoral communication, coordination and collaboration.
- Provision of care within a community-based model is poorly understood on a programmatic level and inadequately discussed among stakeholders, particularly service users and providers.
- Families and carers of people with mental disorders and/or psychosocial disabilities receive little or no support from mental health services.

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### Summary of interventions

Many countries in CEE have adopted international recommendations for standards of care into their reform strategies. Implementation is slow in many contexts, however, and progress is hindered by poor practices such as failure to conduct local needs assessments and to integrate psychosocial services into primary health care systems. The hierarchical structure of mental health care systems has also impeded the development of collaborative models of care and psychosocial rehabilitation (see Box 2).

In Lithuania, for example, adherence to international standards and a focus on bed reduction have strongly influenced reform initiatives. Nevertheless, due to a lack of needs assessments and a failure to adequately strengthen community-based care, primary health care centres solely prescribe medication, services remain compartmentalized and large treatment gaps persist (see also Box 1).

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### Summary of discussion

Participants pointed out the **absence of documented service-user experiences** in the region, and how this relates to a systemic **lack of consideration for their dignity**. Clinicians, for example, commonly discuss treatment plans with family members rather than service users, effectively blocking them from participating in the decisions that affect their lives. Clinicians point out that inadequate time with service users is the main barrier to quality of care, and yet service users report that just 15 minutes of contact can be adequate when clinicians treat them with respect.

This situation highlights an **absence of communication among stakeholders** in the region, perpetuated in part by the education

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### **Box 2. Cultural drivers that facilitate/hinder mental health care reform**

In his presentation, Jack Friedman of the University of Oklahoma's Center for Applied Social Research emphasized the importance of understanding how culture can be operationalized as a core consideration in approaches to mental health care reform in CEE. He explained that culture contributes to:

- societal beliefs about mental illness and recovery;
- clinicians' beliefs about mental illness, treatment and recovery; and
- the political norms required to recognize, prioritize, fund and value reform.

A focus on cultural drivers avoids reducing culture to an "irrational" set of beliefs that stand in opposition to "rational" scientific, medical practices. Instead, it seeks to identify the key sources of support – and neglect – that exist in the many cultures within CEE. It allows stakeholders to approach reform in a sensitive and tailored manner, avoiding assumptions and one-size-fits-all approaches to both processes and goals. Critically, it can also facilitate the reconsideration of some of the cornerstones of reform in the region, such as deinstitutionalization and partnerships with faith-based communities to enhance pathways to and/or continuums of care.

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system. Stakeholder collaboration that includes service users should be embedded within the reform process. Composite clinical indicators of patient outcomes as well as service-user evaluations of care could foster this, as could the implementation of community-based care delivered by multidisciplinary teams.

Understandings of community-based care, however, are relatively vague within the region, and widespread consensus on its meaning is lacking. While it is generally understood as care provided in community settings close to the population served, stakeholders from various fields may disagree on who should provide services, how to define “community”, and what treatment and recovery-oriented services are acceptable. Not surprisingly, **coverage of community-based care in the region remains low**. In some areas, such as Slovakia, community-based care exists but remains inaccessible to the majority of the population.

**Families and carers of people with mental disorders and/or psychosocial disabilities are undersupported** in CEE. While being solely responsible for care can cause severe strain on families, it can also limit the autonomy and freedom of those receiving care to manage their own lives. Addressing this issue requires a multisectoral approach that includes clinical social workers in outreach, education and the development of treatment plans, as well as the allocation of resources outside of institutions.

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## Lessons learned from mental health care reform

This session focused on Czechia’s recent experiences of implementing reform. It examined the cultural assumptions and challenges facing the reform process, the role of public and private institutions, and the potential transferability of the country’s approach to other areas of the region.

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### Key points

- A human rights-based approach to reform is one of the greatest drivers of deinstitutionalization.

- Careful attention to language, especially to convey the rights of people with mental disorders and/or psychosocial disabilities, is integral to effective communication with stakeholders and advocacy for reform.
- Decision-making in service provision lacks transparency, and evaluation is lacking.
- The development of human resources, particularly for community-based services, is key to advancing reform.

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### Summary of interventions

Reform in Czechia, including the commitment towards deinstitutionalization of services, has faced multiple challenges from the outset. These include an ongoing emphasis on psychiatric hospitals, high staff turnover at the Ministry of Health, a shifting political climate, a lack of historical precedent for integrating social sciences into health, relatively low health literacy, pervasive stigmatization, societal expectations for free care, and a lack of systematic monitoring and evaluation within service provision. As existing health services are compartmentalized, determining financial responsibility for service provision has also proven difficult; this has thrown the financial sustainability of the reform into question.

Overall, a lack of funding and political interest combined with inadequate planning has resulted in a reform process prone to stagnation and incremental change. While the recent introduction of financial aid from the European Union has mitigated some of these issues and brought new momentum to the ongoing reform, a lack of clearly articulated goals remains a challenge (see Box 3).

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### Summary of discussion

Participants identified the role of **civil society as a key cultural driver** of the structure of mental health care. They noted the impact

of democratization and increased commitment to civil rights and due process on the advancement of deinstitutionalization and destigmatization. Human rights, as defined in and ratified through the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (12), are solid grounds for advocacy within the region.

However, some translations of the CRPD dilute its meaning or lead to misperceptions, such as that disability is an exclusively physical phenomenon. This highlights the **powerful impact of language** on societal understandings of the rights of people with mental disorders and/or psychosocial disabilities. Close attention to language is essential for successful stakeholder communication and advocacy.

**Decision-making processes in the region are unclear and lack transparency.** Insurance companies' criteria for determining whether services will be covered are poorly understood, and structures or systems to guide the allocation of funds for reform processes are often lacking. The contingency of service provision on insurance providers is

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### **Box 3. Mental health care reform in Czechia**

After the revolution in 1989, psychiatrists and other professionals in Czechia repeatedly advocated for mental health care reform. However, as Petr Winkler of Czechia's National Institute of Mental Health explained in his presentation, these initiatives were not followed through on a governmental or ministerial level until 2011. At that point, the Ministry of Health took the lead on reform.

The availability of European structural and investment funds to finance the transition period of reform has done much to drive forward the Ministry's decision. In 2013, it published a strategy identifying the reform's direction in line with international standards. However, an extensive planning process did not inform this strategy, and the lack of clearly articulated action plans subsequently hindered progress.

The launch of several projects in 2017 bolstered the reform, and significant space remains for shaping their content. Ad hoc planning, mainly by the reform's Executive Committee, is being used to address challenges. Going forward, country-specific assistance in the form of bilateral collaborative agreements between Member States, the Ministry of Health, local stakeholders and WHO could be very helpful; such assistance has been an important driver of building local capacity for community-based care.

Empowering and involving service users remain notable challenges in Czechia. While stigmatization persists, their inclusion as stakeholders at all levels of reform is a priority.

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a barrier to reform, particularly as national health insurance systems rarely cover psychoeducation or psychotherapy.

The **lack of systematic evaluation of mental health care** in the region also impedes progress. Empirical evidence does not adequately inform decision-making processes, and accountability mechanisms are not yet in place. This heightens the risk of corruption in leadership and stifles progress. Additionally, assessing the specific needs of populations in order to match services to those needs is not a standard practice in the region.

The development of **human resources for community-based services** will accelerate progress on reform. Collaborative models can offer low-cost approaches to addressing systemic deficiencies in this area. In Czechia, for example, hospitals are interested in involving students as active contributors to care. While this model is still in its infancy and currently led by nongovernmental organizations, it highlights an opportunity for enhancing the experience of both students and service users.

Mapping **pathways to care** could help countries to better understand when and how people choose to seek help for mental health issues. Churches, for example, are a common point of initial contact for help-seeking in some countries of the region; this stems from the Soviet era when the Catholic Church offered protection to many people with mental disorders and/or psychosocial disabilities.

Countries could also investigate the implications of traditional approaches to treating mental illness. Exorcisms, for example, are still relatively common in some parts of CEE, including Lithuania and Poland. While including local healers in service provision may pose certain risks (for example, to people's confidentiality in rural, tight-knit communities), traditional healing practices for mental disorders are largely accepted in some areas of CEE, such as Armenia. The consideration of local belief systems is important, particularly when and where communities view psychiatric treatment as a last line of defence.

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## Understanding and incorporating subjective experience in policy and practice

This session aimed to explore some of the main research methods and techniques used within the humanities and social sciences in order to outline forms of evidence that could enrich understandings of mental health care. Participants focused on how patient and carer narratives could inform policy and practice.

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### Key points

- Meaningful reform can best be achieved through a mixed-methods approach that combines clinical knowledge with qualitative methods that capture the nuance of lived experience.
- Increasing the use of existing evaluation tools can enhance understandings of care and aid reform.
- The assessment and explicit communication of the needs of stakeholders at all levels can foster more collaboration in reform initiatives.

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### Summary of interventions

Qualitative methods are ideal for researching culture and mental health for many reasons (13). They can capture nuance, build empathy and foster in-depth understanding; are suitable for sensitive topics or fields; can include alternative and silenced voices; and can help make sense of people's feelings, experiences and actions.

**Narrative approaches**, for example, can involve gathering new stories, collating and (re)analysing existing stories, using **ethnography** – prolonged, in-depth, semistructured interviews and observation – to study stories as they are enacted, and studying policy as discourse. Sources of narratives in mental health research are numerous, and might include diaries, stories, drawings, clinical records, policies, popular media, and observations of mental health consultations.

Researchers may also collect narratives through **oral history**, a relational method of historical research conducted through

interviews. Oral history is especially suitable for subjects who have experienced social exclusion and stigmatization, such as those with mental disorders and/or psychosocial disabilities.

**Participant observation**, another qualitative approach often used in anthropology, involves conducting research while playing a participatory role in the community. The resulting data, more richly contextualized than data obtained through nonparticipant observation, is often valued by social policy-makers and can be a powerful tool for advocacy.

Qualitative methods such as these can build understanding of how people with mental disorders and/or psychosocial disabilities and their families experience mental illness. For instance, a study examining family stigma in Belarus found a lack of dialogue and communication between policy-makers and service users that resulted in a vicious cycle of unresponsive health care services and increasingly disempowered users (14). Interviews and focus groups provided insight into carers' deep-seated passivity and resistance to holding positive expectations for mental health care.

These findings may be considered symptoms of post-communist syndrome, also referred to as post-totalitarian syndrome, with manifestations at all levels of society (15). At the individual and community level, disempowerment and distrust are often pervasive. At the institutional and governmental level, policies tend to be paternalistic and top-down in nature, resulting over time in rigid systems that fail to respond to the changing needs and preferences of their beneficiaries. This may partially explain some of the challenges related to mental health care reform in many countries in CEE.

From a service-user perspective, reform should include deinstitutionalization, community-based mental health centres staffed with multidisciplinary teams, complex care without an overprotective approach, opportunities for service users to evaluate care, stigma-reduction efforts to ensure safety and inclusion in society, emancipation support throughout the decision-making processes of reform, and employment and housing opportunities (see Box 4).

Incorporating families' and carers' perspectives can also build awareness of their need for informal support to ameliorate the difficulties of caring and to reduce stigma, as well as state support in the form of social benefits.

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## Summary of discussion

Participants discussed the appropriateness of using qualitative methods to explore and understand the cultural aspects of reform in CEE. They agreed that research from the humanities and social sciences could provide valuable insight into people's subjective experiences of mental health, and build on the foundation of existing diagnostic guidelines. Mixed-methods approaches and multidisciplinary research teams could contribute to the development of a comprehensive research agenda in the region.

Qualitative methodologies such as witness seminars are particularly suited to amplifying the voices of marginalized stakeholders and addressing the expressed needs of communities (see Box 5). Once these needs are understood, their **communication to policy-makers** via locally driven, bottom-up approaches must also be more effective.

Additionally, the majority of countries in CEE already possess a **variety of tools to aid reform**. For instance, economic surveys that pick up on cultural values and markers (such as gender) can provide valuable insight into the structure of services and approaches to their reform. However, countries often underuse these tools or fail to use them at all.

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### **Box 4. Service-user perspectives in mental health care and its reform**

In her presentation, Dana Chrtková of the mental health association Dialogos emphasized that people with mental disorders and/or psychosocial disabilities must be at the centre of the reform process. As the basis for dignified care, service users must know their rights and be in a position to demand them – particularly Article 19 of the CRPD: living independently and being included in the community (12).

The clear conflict between Article 19 and the nature of institutionalized psychiatric care reaffirms the critical need for reform. The development of community-based care delivered by multidisciplinary teams should aim to empower service users to attain the highest level of independence possible.

The respect of all stakeholders for the voices of people with mental disorders and/or psychosocial disabilities is critical for making positive change within the system of care. Service users must play their part by actively advocating for their rights, presenting their opinions and taking an active role in decision-making.

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## Policy and practice implications

Through small-group discussions, participants explored the implications of positive and negative cultures of mental health care on policy and practice in the region. They identified the cultural drivers of greatest priority to reform, and developed recommendations for translating learning into action.

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### **Box 5. Witness seminars**

In her presentation, Sarah Marks of Birbeck, University of London (United Kingdom) focused on witness seminars, a method of oral history research. Witness seminars gather testimony from stakeholders involved in a particular event, such as a policy reform or health initiative to reveal how individuals and groups made decisions, what conflicts arose, and the factors that facilitated or hindered developments.

These subjective recollections provide a source of evidence beyond the content of official documentation. This qualitative data can be valuable for understanding decision-making in policy and reform, the cultural or ideological influences that shaped decisions and actions, and the perceived reasons for the success or failure of interventions. Importantly, they can also offer a starting point for the evaluation of decision-making processes.

To conduct a witness seminar, organizers invite individuals who played a key role in a particular intervention (health professionals, service users, policy-makers, etc.) to attend a concentrated discussion framed around questions predetermined by the research team. An individual independent of the group concerned chairs the discussion. It is recorded, and the audio recording and transcript can be made available for research purposes. Organizers may also invite participants to prepare a short brief, circulated to all members of the seminar in advance, to initiate recollections and discussion.

A witness seminar held at the University of Oxford (United Kingdom), entitled *The UN and humanitarian action: learning lessons from past experience for future policy* (16), provides an example of this method of oral history research.

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## Key points

- Ethnographic approaches are appropriate for investigating decision-making and its evaluation.
- Oral histories and witness seminars can effectively document service-user perspectives, and their results can be used to increase collaboration among stakeholders.
- The triangulation of data collected via ethnographic research methods, focus groups, online surveys, key informant interviews and expert analyses can reveal understandings of community-based care.

## Summary of small-group work identifying key cultural drivers of mental health care reform

In order to rank the relevance and importance of cultures of reform in the region, participants identified and cast votes for two cultural aspects of greatest priority to mental health care and its reform in CEE. The following three emerged as key cultural drivers:

1. cultures of **decision-making in service provision** and the evaluation of decision-making processes;
2. cultures of **collaboration among stakeholders**, particularly service users and their families; and
3. cultural understandings of **community-based care** among various stakeholders.

## Recommendations for translating learning into policy and practice

Participants reflected on the content of the workshop in order to make actionable research and policy recommendations. The following sections detail their recommendations for each of the key cultural drivers.

## Cultures of decision-making in service provision and the evaluation of decision-making processes

Participants recommended the following research questions for the future evaluation of decision-making in service provision.

1. who are key players in the process of decision-making for mental health care and its reform?
2. how do insurance companies in the region decide where to dedicate funds?
3. on which criteria are services deemed investable?
4. what processes drive decision-making for mental health care and its reform?

They recommended ethnographic approaches to further investigate this cultural driver, noting that these initiatives should be led by individuals in situ in order to foster local insight.

They also proposed the collection of country case studies to provide context-specific analyses of several factors: political situations; past and current health system trends; historical factors influencing reform in different contexts; the impact and role of international agencies such as the European Union and WHO; evolutions in economic development and funding allocation; and financing structures and mechanisms that could aid reform initiatives.

Finally, they suggested that the evaluation of decision-making processes could become a measure of reform activation. They pointed out that as new reform measures (including the evaluation of decision-making) are introduced, the experiences, needs and priorities of service users and their carers will likely shift and new issues and concerns will arise. Continued needs assessments and monitoring/evaluation should be carried out to ensure that these are adequately addressed.

### Cultures of collaboration among stakeholders, particularly service users and their families

Participants agreed that in order for service users to feel empowered and supported to share their perspectives, they must be met with a variety of platforms and opportunities to do so. In addition to oral histories and witness seminars, these platforms could include community dialogues using the Human Library framework to initiate conversations that break down stereotypes and prejudice (17), and face-to-face interactions with decision-makers and policy-makers to build understanding and consensus.

They emphasized that working towards a culture of positive language is also essential. This involves shifting the terminology used for and by people with mental disorders and/or psychosocial disabilities from that of passive victimhood to active citizenship, emphasizing their work to challenge stigma, overcome difficulties and live positively within their communities.

### Cultural understandings of community-based care among various stakeholders

Participants recommended the following research questions to explore the meaning of community-based care in CEE.

1. What does community-based care mean to various stakeholders?
2. What discrepancies exist among stakeholders in terms of how community-based services are seen and idealized?
3. What are stakeholders' anticipated or desired roles, and what expectations do they hold for the structure of these roles?
4. What does treatment and recovery mean to various stakeholders?

Based on these questions, they suggested creating mixed-methods research initiatives to elucidate cultural conceptualizations of community-based care. Ethnographic research could be used to develop a set of research protocols for application at all levels of communities and for specific target populations. This work should be preceded by a situational analysis to understand national drivers of reform.

Methods could include focus groups, online surveys, key informant interviews and expert analyses. Data from all sources should be analysed and triangulated, and subsequently validated by respondents. Findings should be disseminated to all levels of communities to advocate and build consensus for reform, using appropriate language for different groups.

In closing, the group suggested mechanisms to drive forward policy and practice for the reform of mental health care in CEE (see Box 6).

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#### ***Box 6. Recommended mechanisms for translating learning to policy and practice***

- Build multisectoral advisory groups for consultations on various issues in reform, initiating both open meeting logs for reform processes and closed meetings with policy-makers or clinicians to understand motivations and preferences.
  - Conduct pilot studies of collaborative models of care to address scepticism from policy-makers and serve as proof of concept for scaling up reform initiatives.
  - Legitimize local stakeholders who drive reform forward as ambassadors at various levels to ensure sustainable momentum and investment in reform.
  - Cater language to different audiences to effectively communicate evidence and stakeholder perspectives.
  - Collect case studies of deinstitutionalization to learn from comparable communities and address local contexts.
  - Develop incentivization schemes targeting funders to support community-based care centres.
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## Conclusion

In CEE, the history of communist forms of government has contributed to shaping the contemporary social, economic, political and cultural climate, and to the related challenges currently facing mental health care reform. Barriers to reform exist at multiple levels, and include a lack opportunity for civil society to engage in advocacy; high levels of disempowerment among service users and their families/carers; an overreliance on top-down, institutional approaches; the compartmentalization of care; opaque decision-making processes; and corruption within psychiatric institutions.

Despite such challenges, reform of mental health care is gaining traction in CEE. Promising opportunities exist for addressing the cultural aspects of these reforms, and research in this area can help to deepen understandings of and overcome hindrances to the work ahead. It can also highlight various enabling cultures within the region that can be leveraged to further drive positive change.

Ethnographic research methods provide useful applications for exploring the cultural aspects shaping mental health care in CEE. They can help countries to understand the decision-making processes currently in place, and to evaluate their effectiveness in the coming years. Narrative approaches such as oral histories and witness seminars can be used as tools for surfacing the experiences and perspectives of people with mental disorders and/or psychosocial disabilities, which is critical to their empowerment and the overall success of reform.

The process of deinstitutionalizing services while simultaneously developing community-based models of care that uphold the dignity and rights of service users necessitates multisectoral collaboration. Building cultures of communication among all stakeholders can foster this collaboration by unearthing similarities and disparities in conceptualizations of care, providing opportunities to unify ideologies, and prompting inclusive discussions on the creation of systems in which all stakeholders become beneficiaries.

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## Annex 1. Programme

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Monday, 2 October 2017

### **Opening**

Welcome and introduction

Briefing on workshop objectives

### **Session 1. Historical and cultural drivers of reform**

#### **Presentations**

- Sarah Marks: history of psychiatry and psychotherapeutics in CEE
- Miroslava Janoušková: stigma and mental health
- Robert von Voren: sociocultural drivers of mental health care

#### **Discussions**

- How have cultural norms, understandings and expectations affected policy-making related to mental health care?
- How have conceptions of mental health changed within CEE and what are the key cultural drivers accounting for this?
- What are the main areas of convergence and difference in experience across the region?

### **Session 2. Cultural aspects of mental health care reform**

#### **Presentations**

- Jack Friedman: cultural drivers that facilitate/hinder reform
- Arunas Germanavicius: psychosocial rehabilitation

#### **Discussions**

- How can understandings of cultural norms and concepts be most effectively used to help underpin mental health care reform and provide evidence of the development of mental health care?
- What social and cultural factors hinder reform and how can this be addressed in a culturally sensitive manner?
- What does community-based care mean across the diverse cultural contexts of CEE?
- How can families and communities be most effectively supported in their role as care providers?



### Session 3. Lessons learned from mental health care reform

#### Presentations

- Petr Winkler: the experience of reform in Czechia
- Alena Šteflová: the challenges of implementing reform
- Helena Rögnerová: financial challenges related to reform

#### Discussions

- Why has deinstitutionalization and mental health care reform been achieved in some countries and contexts, and not others?
- What cultural norms and assumptions underpin reform and notions of care, and what are the implications of this for policy and practice?
- What is the role of public and private health care providers in facilitating reform?
- What are the key cultural insights from European countries for Member States that are currently engaging in reform processes?

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#### Group work. Policy and practice implications from Day 1

##### Points for discussion for group work

- What do you consider to be key cultural influences on, or drivers of, mental health and mental health care? How can elucidation of these factors:
  - facilitate reform and the development of evidence-based mental health care;
  - be used to effectively communicate mental health-related issues to policy-makers and the public; and
  - improve people's attitudes towards mental health and illness?
- What are the key research needs and gaps in relation to the cultural contexts of mental health care and its reform?
- How can policy-makers be encouraged to engage with or learn from cultural influences and contexts when driving reform? Is there an example worth highlighting?

##### Summary by rapporteurs from group work

##### Conclusions of Day 1 (Chair and WHO Secretariat)

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Tuesday, 3 October 2017

### Opening

- Summary of Day 1 (Chair)
- Background and ambitions for Day 2

## Session 4. Understanding and incorporating subjective experience in policy and practice

### Presentations

- Simina Badica: oral history
- Felicity Thomas: narrative approaches
- Anna Klepikova: ethnographic approaches
- Dzmityry Krupchanka: incorporating the experiences of carers
- Dana Chrtková: service users' experiences

### Discussions

- How can we draw on methods and approaches from the humanities and social sciences to better understand the challenges and opportunities to mental health care presented by social and cultural norms?
- What opportunities exist for such methods and approaches to be used in a way that complements biomedical and health services research?
- What are the logistical and ethical implications of incorporating service-user collaboration and involvement in mental health policy and practice?
- How can individuals be empowered through research, policy and programming, and what are the roles and responsibilities of diverse state and community institutions within this?

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## Group work. Translating learning into policy and practice

Points for discussion for group work

- What methodological approaches from the humanities and social sciences are most amenable to informing policy and practice? Is there an example worth highlighting?
- What mechanisms need to be put in place to help translate learning from the humanities and social sciences into policy and practice?

Summary by rapporteurs from group work

Conclusions of Day 2

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