

Perspective Piece

A reflection on the role of individuals with lived experience in shaping the Brazilian psychiatric reform

C.M. Corradi-Webster¹ , G. Reis² , E.B.V. Brisola³ , C.A. Sampaio⁴ , C.N.P. Araujo⁵ , L.S. Rufato⁶ ,
R.A.S. Oliveira⁷ , R. Éllen Cristina Ricci⁸ , W.F. de Oliveira⁹ , B.R. de Oliveira¹⁰ , C. Bellamy¹¹  and M. Costa¹¹ 

¹Department of Psychology, Faculty of Philosophy, Sciences and Letters, University of São Paulo, Ribeirão Preto, Brazil, ²Yale School of Medicine, Project Coordinator at Program for Recovery and Community Health, School of Medicine, Department of Psychiatry, Yale University, New Haven, USA, ³Medical Sciences Graduate School, Belo Horizonte, Minas Gerais, Brazil, ⁴Program of Graduate studies in Sciences and Health, Department of Mental Health and Community Health, State University of Montes Claros, Montes Claros, Brazil, ⁵Department of Psychiatry, University of Florida, Gainesville, USA, ⁶Psychology Department, Municipal University of Franca, Franca, Brazil, ⁷Workers Mental Health Coordination, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil, ⁸Department of Neurosciences and Mental Health, School of Medicine (Occupational Therapy) at Federal University of Bahia (UFBA), Salvador, Brazil, ⁹Department of Public Health, Federal University of Santa Catarina, Florianópolis, Brazil, ¹⁰Master candidate in Public Administration, Student at João Pinheiro Foundation, Belo Horizonte, Brazil and ¹¹Program for Recovery and Community Health, School of Medicine, Department of Psychiatry, Yale University, New Haven, USA

Abstract

In the last ten years, the recovery movement has significantly influenced mental health services and workers, psychiatric reform, and the advocacy movement worldwide. Within Brazil's public mental health care system, operates a cohesive, powerful advocacy coalition empowering recovery-oriented practices. This article aims to highlight successful initiatives spearheaded by individuals with lived experience in Brazil. We will also present some challenges, and discuss possible recovery strategies to strengthen mental health services by empowering people with lived experience and promoting social justice. Efforts and initiatives to implement recovery strategies in Brazil are underway, aiming to improve population mental health and substance misuse both within and outside mental health services. These initiatives include peer support, advocacy, testimonies and empowerment, employment, and social, cultural, and artistic initiatives. Some of the challenges to greater participation of individuals with lived experience in this ongoing process of Brazilian psychiatric reform include the following aspects: barriers to the autonomy and independence of lived experience organizations; the longstanding history of racism in Brazilian society; disparities in social indicators such as education and income, between professionals and people with lived experience in mental health and substance misuse. Although progress in Brazil's psychiatric reform has advanced through recovery initiatives, challenges remain in ensuring leadership roles for people with lived experience. Ongoing success depends on their active involvement, alongside advocacy movements and involvement of broader society.

Keywords: Brazil; peer support; public mental health; recovery; serious mental illness

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Introduction

Brazilian psychiatric reform movement

Psychiatric reform in Brazil in the past exposed the failures of policies that confined individuals with serious mental illness to psychiatric hospitals. This reform was supported by anti-asylum social movements, such as the Anti-Asylum Fight Movement and the Internúcleos Anti-Asylum Fight (Amarante & Nunes, 2018). Between 2016 and 2022, the federal government led an effort to defund Brazil's public health system, leading to reduced funding for public community-based mental health services and an

increased push for funding for psychiatric hospitals – spearheaded by the Brazilian Psychiatric Association (Amarante & Nunes, 2018; Onocko-Campos, 2019). Despite these setbacks, there are several anti-asylum social movements in Brazil, along with mental health workers and social organizations advocating for public health and the Brazilian National Health System (Sistema Único de Saúde – SUS), striving to implement various strategies for social inclusion and justice for people with serious mental illness. These strategies are developed and implemented through participatory processes with input from individuals with lived experience of mental illness. Although significant progress has been made, challenges remain to be addressed, such as increasing the involvement of individuals with serious mental illness in developing public policies, service planning, and providing peer support.

In 1978, the Mental Health Workers Movement emerged in Brazil, advocating for dignified care. Psychiatric hospital workers harshly criticized the services they were part of, highlighting the

Corresponding author: Mark Costa; Email: mark.costa@yale.edu

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numerous human rights violations experienced by people in these places and exposing the profit-driven market behind these institutions (Amarante & Nunes, 2018). Over time, this movement gained support from people with lived experience, their families, professional associations, and other community members. It strongly influenced Brazilian psychiatric reform, drawing inspiration from Basaglia's anti-asylum movement that originated in Italy (Mângia & Nicácio, 2001).

In 1990, Brazil signed the Declaration of Caracas, which advocated for significant changes in treating individuals with mental illness that prioritized community-based care (Jacob *et al.*, 2007). Subsequently, in 2001, the Paulo Delgado Law was passed, leading to the establishment of community mental health services known as Psychosocial Care Centers (CAPS). This law led to the closure of numerous psychiatric hospitals, redirecting the care model toward community care. By enforcing decrees and ordinances that expanded access to resources and services in the community, this law empowered people with lived experience in mental illnesses and substance misuse. It enabled them to establish a sense of belonging and meaningful lives within the community and ensured their full access to their civil rights. Before this legislation, Brazil's mental health system faced significant challenges, including the restriction of access to rights, insufficient resources, inadequate treatments, and a lack of well-integrated community services. The Paulo Delgado Law was essential in filling these gaps by enhancing leadership, introducing innovative strategies, and establishing regulations aimed at improving mental health care (Brasil, 2001).

In the last ten years, the worldwide recovery movement has influenced mental health services and workers, psychiatric reform, and the advocacy movement in Brazil. Recovery is described as a unique process that involves empowering one's life, developing new skills, and finding a meaningful purpose (Davidson, 2017). Functioning as a cohesive and influential advocacy coalition, it promotes the leadership of individuals with lived experience and strengthens recovery-oriented practices within the Brazilian public mental healthcare system. All the authors of this article are committed to this movement and are actively engaged in developing practices that expand participation, through our work as academics, healthcare providers, and individuals with lived experience. We aim to share successful initiatives led by people with lived experience in Brazil, highlight challenges such as racism, and discuss potential recovery strategies to enhance mental health services by empowering individuals with lived experience and promoting social justice.

Engagement of people with lived experience in Brazilian psychiatric reform

Several initiatives in Brazil aim to improve mental health and substance use both inside and outside mental health services. Efforts to implement recovery strategies are also underway. These initiatives include peer support, advocacy, the creation of spaces for sharing experiences and empowerment, as well as employment and social, cultural, and artistic programs, as described below.

Peer support

In Brazil, peer support initiatives are growing exponentially and becoming essential strategies to advance mental health services. Three experiences shared in this paper illustrate some of these

ongoing initiatives: the Hearing Voices group, the Brazilian Association of Friends group, and the Arautos do Mundo project.

The Hearing Voices Group in Ribeirão Preto was established in 2015 to provide a space for individuals who experience hearing voices to share their perspectives and attribute new meanings to this phenomenon (Rufato *et al.*, 2021). Although professionals initially facilitated the meetings, the group is now coordinated by people with lived experience, who have also gradually expanded their participation in other spaces, including national and international conferences.

Currently, four groups are active: one within a mental health service, one online, via WhatsApp, and another at a cultural center open to all community members. The strength of peer support lies in its ability to foster empathy, acceptance, and understanding to those in similar journeys. By sharing their stories, participants gain deeper knowledge of their own experiences, learn from one another, and feel empowered to shape the course of their lives (Rufato *et al.*, 2023). This peer support group played a pivotal role in securing a municipal law combating stigma. Establishing an official awareness day enhances the visibility of this historically marginalized group and empowers its members by creating opportunities for dialogue and social mobilization.

The Brazilian Association of Friends, Relatives, and Persons with Schizophrenia in São Paulo is another Brazilian peer support initiative that provides support to people with schizophrenia disorder and their family members, and is focused on exchanging mutual experiences (Corradi-Webster *et al.*, 2023).

Currently, the city of Campinas is conducting NIMH-funded research to adapt and implement peer support strategies aimed at optimizing engagement and outcomes for people with serious mental illness at the Psychosocial Care Centers. As part of this initiative, the peer support curriculum has been translated and culturally adapted, and is now being used to train a group of peer supporters and mental health workers.

Advocacy, testimonies, and empowerment

In the Brazilian psychiatric reform movement, human rights and empowerment were critical principles in shaping, transforming, and establishing community-based mental health care. The three groups have potentially influenced public policies in Brazil.

The documentaries 'Hearing Voices' (Tarpani, 2017) and 'Women Who Hear Voices' (Freitas, 2021) explore the testimonies of people with lived experience and their families, illustrating how they construct meaning for these voices in their daily lives. These films discuss the stigma surrounding voice-hearing and challenge societal constructions of normality (Tarpani, 2017), aiming to encourage community conversations within other hearing voices groups in Brazil (Moraes *et al.*, 2023).

Two grassroots organizations in the state of Minas Gerais – the Mental Health Mineiro Forum and the Association of Mental Health Service Users of Minas Gerais – have demonstrated increasing interest in innovative peer-led initiatives and their potential to help advance psychiatric reform in Brazil. These organizations advocate for social justice by addressing systemic inequalities, combating stigma, and promoting inclusive and participatory mental health policies that reflect the diverse needs of Brazil's population. They discuss how recovery strategies led by people with lived experience in mental health and substance use and family members regarding recovery, peer support, hearing voices, and other recovery-oriented strategies within advocacy

organizations, have led to meaningful advancements in advocacy and policy.

Mental health conferences held throughout Brazil have the potential to change policies across the 27 federative units. As a result, the final document of the 5th National Conference on Mental Health will direct the Brazilian public mental health policy, incorporating the terms *recovery* and *peer support* in the final document for the following years. Additionally, harm reduction policies – one of the first national policies involving individuals with lived experience in public health – have been in place for over thirty-five years.

Employment

People with lived experience have been professionally employed as caregivers, supporting others undergoing similar experiences, particularly in substance use treatment and harm reduction services. A qualitative study with harm reduction workers across different states in Brazil (Pedroso *et al.*, 2024) highlighted their critical role in advocating for the rights of people who use drugs and providing low-threshold treatment. Their approach was guided by goals tailored to individual needs, without restrictive access criteria and ensuring greater autonomy in the care process. Their lived experience enhanced their ability to demonstrate greater empathy, understand the challenges faced by those they support, and communicate in ways that resonate with them.

A notable harm reduction initiative conducted by individuals with lived experience is currently underway in Belo Horizonte (Vieira *et al.*, 2023). Although the profession of harm reduction with lived experience is not yet officially regulated in Brazil (Pedroso *et al.*, 2024), Belo Horizonte has formally employed harm reduction workers with lived experience in substance use through official employment contracts (Corradi-Webster *et al.*, 2023). These workers are involved in street outreach, provide support at community-based mental health centers for substance use, and work within community-based mental health centers for children and adolescents (Vieira *et al.*, 2023).

Social, cultural, and artistic initiatives

Social, cultural, and artistic activities play a central role in integrating individuals with lived experience into their communities while deconstructing stigma. In the same year the Paulo Delgado Law (2001) was enacted, patients and professionals from the Municipal Institute Nise da Silveira – the largest and oldest psychiatric hospital in Brazil – founded the carnival group Loucura Suburbana (Oliveira & Cardoso, 2020). The initiative aimed to promote deinstitutionalization through Brazil's most celebrated cultural festival: Carnival. Since its creation, the group's parade themes have centered on mental health, inclusion, and the stigma surrounding mental illness (Oliveira & Cardoso, 2020).

Over time, Loucura Suburbana has expanded and now involves people with lived experience in mental illnesses from various mental health services in the city of Rio de Janeiro, as well as their family members, mental health professionals, and community members. All participants actively contribute to costume design, samba song composing, and the organization of the annual carnival parade (Mendes, 2019). This involvement in the entire process fosters a sense of agency and empowerment. In preparation for the annual carnival parades, members engage in music workshops, costume design workshops, general rehearsals, income-generating workshops, and samba circles provided by the Institute (Oliveira & Cardoso, 2020). During the carnival parade,

people with lived experience perform as samba dancers and percussionists in the Institute's neighborhood streets. By encouraging the public presence of people with lived experience in the city's streets, individuals who were confined in psychiatric hospitals for many decades, and by promoting the co-production of a major cultural event alongside their community, the project has promoted citizenship and contributed to reducing the mental health stigma.

The Arautos do Mundo project is a peer support initiative dedicated to empowering Black and Indigenous people and mental health users. Hosted at the Institute of Psychiatry at the Federal University of Rio de Janeiro, the project ensures the creation of new spaces for social interaction within the city (Oliveira, 2023). Over the past seven years, it has orchestrated a diverse range of activities, including '*cordel*' (a traditional Brazilian folk poem form). The project incorporates anti-racist and anti-ableist initiatives proposed by Black and Indigenous leaders, ensuring that all participants play an active role in shaping actions that promote an anti-racist agenda. These efforts include public performances, cultural occupations, and exhibitions performed by Black and Indigenous collectives and individuals with lived experience.

Emphasizing the significance of representation, all anti-racist activities necessarily include Indigenous and Black individuals, as well as those with lived experience. For these groups, being valued as protagonists in cultural and social initiatives is profoundly empowering. Their participation has significantly contributed to the deconstruction of stigma and ableism (Projeto de Extensão Arautos do Mundo, 2024).

Challenges in implementing the recovery approach in Brazil

To examine the challenges hindering greater participation of individuals with lived experience in the ongoing process of Brazilian psychiatric reform, we analyzed the following aspects: barriers to the autonomy and independence of lived experience organizations; the persistent history of racism in Brazilian society; and disparities in key social indicators such as education and income, between mental health and substance use professionals and people with lived experience.

Barriers to advance psychiatric reform

One focus of Brazilian psychiatric reform has been on enhancing access to psychosocial rehabilitation services. The movement has emphasized the reorganization of services and the closing of psychiatric beds to provide mental health care in the community. Rooted in a collective approach to mental health policies, this movement focused on ensuring human rights by building a network of community-based mental health services. It emerged in the late 1970s, driven by professionals aligned with various labor and leftist movements during Brazil's civil-military dictatorship.

Unlike in other countries, where psychiatric reform was often initiated by user dissatisfaction, the Brazilian movement was primarily led by mental health workers. Outraged by their predetermined roles within these institutions, known for their numerous, grave human rights violations of people with lived experience, these professionals sought systemic change. The reform was heavily influenced by Italy's democratic mental health reform, which transformed services for people experiencing emotional distress by providing care based on human rights and closeness to their community. Brazilian psychiatric reform is closely linked to the establishment of the Brazilian National Health System (SUS) in the 1988 Constitution and was further

strengthened by the rise of progressive governments in the early 2000s. The process of re-democratization and psychiatric reform facilitated the establishment of nationwide mental healthcare networks, leading to a significant expansion of community-based services (Onocko-Campos, 2019). While some major cities saw strong civil society participation in implementing these reforms, this social involvement did not extend successfully across the country. Consequently, psychiatric reform advanced primarily as a public health policy rather than as a result of civil society demand (Onocko-Campos, 2019). In this scenario, the mental health care model continued to be dominated by traditional psychiatry, relying on psychiatric diagnosis and medication, while maintaining a hierarchical division between workers and service users (Leão & Corradi-Webster, 2018). Another barrier to reform is the rigidity of the Brazilian legal system, which considers all individuals diagnosed with a serious mental illness to be legally incapable.

According to Goffman (2009), there is a mortification of the self in totalitarian institutions that causes the loss of all personal characteristics and life histories. Consequently, people follow rules, obey, and lose autonomy and individuality. Foucault (2021) also contributes to this discussion with his theories on the relationship between power and knowledge and how they are used as a form of social control through what he calls 'disciplinary institutions', in which workers often expect obedience from service users, who, in turn, fear questioning or disobeying instructions due to potential repercussions.

Over time, the psychiatric movement gained the support of individuals with lived experience of mental illnesses and their families, evolving into a broader initiative known as the Anti-Asylum Movement (Goulart, 2006).

Structural racism in mental health care

In Brazil, the limited development of public social welfare programs, coupled with the country's racist and hierarchical colonial heritage, has left deep cultural and political marks on social activism and the relationship between professionals and institutions. This legacy has opposed the autonomy and empowerment of people with lived experience (Vasconcelos, 2013). Consequently, the mental health field remains dominated by white professionals and state agents (Vasconcelos, 2013). This dominance has weakened activism, limited the empowerment of people with lived experience, and restricted the representation of diverse societal levels in governmental decision-making. Accordingly, it is essential to consider the role that racism has played in restricting the inclusion and agency of the popular classes in Brazil, where two-thirds of its history was marked by the enslavement of Black and Indigenous peoples.

Today, there remains enormous resistance to implementing public policies aimed at historical reparation and the inclusion of these racial groups, despite their constituting the majority of the Brazilian population (Cunha, 2012; Faustino, 2017; IBGE, 2024). Belief in a (supposed) harmonious racial miscegenation still permeates our society – a myth of racial democracy that creates a fog of normality around the structured character of Brazilian racism. This is exacerbated by the historical absence of support from both Black and White individuals in positions of power within the health sector for anti-racism advocacy, the production and validation of scientific knowledge in health, and the governance of the Brazilian Public Health System. Therefore, advancing democratization within the mental health field requires the representation of Black and Indigenous individuals with lived

experience among those shaping public policies and health services.

A new perspective must be adopted to inform the development of public policies, the operation of public health services (Brasil, 2006), the development of the health system (Batista & Monteiro, 2017), and discussions on the anti-asylum movement (Passos, 2018). With this, Brazil could overcome the denial of the myth of racial democracy and the fog of normality that sustains systemic racial inequalities.

Social determinants among mental health workers and service users

Brazil faces significant inequalities that affect access to education and the ability to remain in school. Disparities in education and income between mental health professionals and individuals with lived experience in mental health services can hinder the establishment of more equal relationships. A study conducted at a Psychosocial Care Center in the Federal District found that 47% of individuals with lived experience in mental health had not completed high school, with some being illiterate. Among them, 55% had worked in occupations that did not require formal education, 30% earned between 1 and 3 minimum wages, and 13% earned less than one minimum wage (Campos *et al.*, 2021). Furthermore, in mental health services, these lower levels of education and income are also intersected by racism.

Brazil faces a significant challenge in the field of social participation, due to its vast socioeconomic inequalities and the substantial educational gap between service users and health workers (Onocko-Campos, 2019). This gap may hinder the implementation of the fundamental principle of Brazilian psychiatric reform: promoting the citizenship and autonomy of people with lived experience. One risk arising from this gap is the persistence of hierarchical relationships within community mental health services, where practices focus exclusively on symptom identification and treatment. This leads to the fragmentation between knowledge and practice, causing workers to adopt an 'expert' stance, working for rather than with users, and undermining the participation of people with lived experience in their recovery process.

A qualitative study conducted with workers from Psychosocial Care Centers (CAPS) revealed that hierarchical structures, characteristic of asylum-based models, continue to prevail. Findings indicated that workers did not view service users as individuals with diverse needs but instead focused exclusively on symptom remission, adopting a pharmacotherapy-centered approach. No attempt was made to establish a collaborative partnership that would allow people with lived experience to participate in decisions regarding their own treatment. Instead, service users and their families were merely given instructions on medication use and were regarded as passive in the care process (Feitosa *et al.*, 2022). As a result, the CAPS failed to establish themselves as spaces that promote recovery by fostering autonomy, enabling the development of different social roles, and strengthening community belonging. Instead, they functioned primarily as chronic care services centered on medication prescription (Nunes *et al.*, 2016).

Another study conducted at CAPS for substance use in three Brazilian states found that the overwhelming majority of mental health users were Black (42%) or mixed race (17%), had no formal education (3%) or had incomplete high school (65%), and had a family income of up to two minimum wages (71%) (Silva *et al.*, 2020).

Bento (2022) critically examines and questions the role of whiteness and its harmful consequences for social relations in Brazil, highlighting numerous instances where Black people were denied job opportunities despite having the necessary qualifications. This research investigates this silent model of the 'narcissistic pact of whiteness', an unspoken agreement of self-preservation that serves the interests of certain groups and maintains the power of white people in public policy and health services (Bento, 2022).

Although laws enacted in the past 12 years have ensured admission quotas for Black, mixed-race, and Indigenous people in public universities, these measures remain insufficient to provide necessary reparation for centuries of injustice (Bento, 2022). In response, initiatives led by individuals with lived experience have been encouraged to address these enduring inequalities and historical marginalization. Efforts to combat stigma, expand rights, create income-generating opportunities, and strengthen peer support networks are essential in addressing the social determinants that limit equitable participation in both mental health services and society as a whole (Onocko-Campos *et al.*, 2021).

Discussion

Significant challenges remain in mental health and substance use services in Brazil, where remnants of hierarchical power dynamics between professionals and people with lived experience in mental health continue to persist. Additionally, the pervasive structural racism in Brazilian society perpetuates unequal relationships among its members. Educational disparities intersect with racism, often placing workers and individuals with lived experience in opposing positions. These are some of the challenges the Brazilian anti-asylum movement must address to ensure recovery processes in which individuals with lived experience take center stage in services and fully integrate into the community. Despite these challenges, this article has highlighted various initiatives in which people with lived experience have taken a leading role and influenced public policies.

Vasconcelos (2013) proposes that empowerment involves increasing the power and autonomy of individuals and groups who have experienced discrimination and oppression in institutional and interpersonal relationships. Some strategies for empowerment, such as peer support, advocacy, popular education, community mobilization, and access to information, facilitate the sharing of knowledge and resources. This enables individuals to make informed decisions about their treatment and actively participate in creating a recovery plan that best meets their needs.

Regarding peer support, it is essential to ensure its sustainability through ongoing peer training and the provision of paid work or grants for facilitators, funded through agreements, the SUS, or income and employment projects (Vasconcelos & Santos, 2011). Additionally, it is critical to train healthcare providers so they understand the work performed and recognize the effectiveness of care provided through peer support. Often, this work is not acknowledged as valuable by the professionals themselves (Pedroso *et al.*, 2024). Furthermore, it is important to disseminate strategies already implemented in Brazil and adapt peer support models from other countries to the Brazilian context. National research support is also essential to explore the characteristics of implementation and evaluate the effectiveness of these strategies, as scientific data can play a crucial role in influencing decision-makers to adopt these initiatives and shaping public policies.

Advocacy is also essential in expanding the participation of people with lived experience. It is important to encourage their

presence in different spaces, through lectures, participation in events, and the organization of groups in cultural and community spaces, aiming to dismantle stereotypes about people with mental disorders. The establishment of networks and alliances can further strengthen advocacy efforts, fostering partnerships between social movements, peer support groups, universities, and international organizations. These collaborations help expand, validate, and sustain the leadership actions of people with lived experience.

This article highlights various experiences of empowerment among individuals with lived experience, showcasing the vibrancy and creativity of Brazil's psychiatric reform and recovery movements, which could be further enriched through international partnerships with experienced peer support and participatory research groups. Such collaborations would contribute to advancing psychiatric reform and recovery movement in Brazil. Through this movement, the voices of people with lived experience have gained increasing prominence, demonstrating that the Brazilian mental and collective health is closely tied to social issues, citizenship, the fight against inequalities and prejudice, and, ultimately, political and democratic concerns.

Conclusions

For the last ten years, individual and collective recovery strategies have overcome obstacles to their full implementation within the Brazilian mental health care system. They operate as a cohesive, powerful advocacy coalition empowering recovery-oriented practices, thus successfully contributing to the advancement of Brazilian psychiatric reform.

Recovery initiatives are present in major cities across Brazil, having been driven by mental health professionals engaged in Brazilian psychiatric reform movement. Having previously worked to dismantle asylum-based care and implement community mental health services, these professionals recognized that deinstitutionalization alone was not enough. They sought new approaches to addressing mental suffering and supporting individuals in leading meaningful lives beyond clinical treatment. Thus, they advanced initiatives focused on social justice and social inclusion through education, training, social interaction, participation in the solidarity economy, and other initiatives empowering people with lived experience, their families, researchers, advocacy movements, and mental health workers.

Brazil's psychiatric reform has made progress through recovery initiatives; however, several challenges remain. The deep-rooted issues of structural racism and significant deep social inequalities continue to impact mental health services. These factors not only hinder access to education and employment for individuals with lived experience but also reinforce hierarchical relationships between service users and professionals. Since many individuals with lived experience often have lower levels of formal education and fewer economic opportunities, their involvement in decision-making processes within mental health services remains limited, perpetuating the hierarchy position between professional and mental health users. In response, recovery-oriented strategies – such as peer support networks, participatory advocacy, and employment policies inclusive of people with lived experience – are essential to redistributing power, fostering more horizontal relationships, and ensuring that service users assume leadership roles in mental health services.

For recovery-oriented care in mental health services in Brazil to advance, professionals must change their approach from being tutors and experts to becoming allies and partners. To support this

shift, academics in this field should advocate within their institutions to ensure that the training of professionals aligns with this move away from a guardian mentality and promotes service users' empowerment.

In the legal realm, it is crucial to recognize the negative implications of denying the rights and social roles of individuals diagnosed with serious mental illnesses. Such exclusionary practices reinforce stigma and create a cycle of dependency, making it difficult for these individuals to engage in meaningful social lives, which is essential for their recovery. The more restrictive the power dynamics in care become, the greater the obstacles to improving service users' conditions, ultimately harming society as a whole.

To advance recovery-oriented care in mental health services, it is essential to challenge these barriers and promote policies that allow individuals to work while maintaining access to necessary social protections. Expanding access to peer support, advocacy networks, and participatory decision-making structures can help create a system that prioritizes inclusion, autonomy, and empowerment over restriction and dependency.

Therefore, actions to address barriers to the advancement of the recovery movement require a complex level of organization that must be exercised in the context of a broader movement with a deep commitment to reforming the Brazilian system as a whole. From this perspective, we understand that the Brazilian Psychiatric Reform movement is currently undergoing a phase of reformulation and reconstruction following the setbacks of the past decade, which have intensified in the last five years. The recovery movement offers valuable insights that can enhance mental health and promote society's well-being. In this article, we aim to contribute to this ongoing journey of progress and understanding.

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