

# *Mental health care and the political participation of users and families in the resignification of stigma on mental disorders*

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**Abstract:** The persistence of stigma associated with mental disorders is a problem that health systems must face in the fight against discrimination of people who experience psychological distress. This qualitative narrative study aims to understand the experience of living with the stigma related to mental disorders from the reports of users and family members of people assisted in Psychosocial Care Centers in different regions of the city of Fortaleza-CE. Four users and three family members who kept the particularity of belonging to a nucleus of the anti-asylum struggle were interviewed. Through a script with questions about individual experiences in the search for care, the information produced was analyzed by the method of dialectical hermeneutics. The results show that stigma is still present in everyday life, implying suffering and discrimination of these people. However, the mental health care processes received, which were oriented towards the recognition of the potential and condition of political subjects, gave new meaning to negative perceptions about themselves and about the services in which they were treated. This process contributed with the engagement of users and family members in official instances of social control and in the anti-asylum movement, instigating, among the subjects, the defense of humanized care and the fight against stigma.

► **Keywords:** Social stigma. Mental disorders. Mental health. Personal narrative.

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## Introduction

Stigma related to mental disorders is a social phenomenon that is worrying because of its persistence. Even with the purpose of the Psychiatric Reform to produce sociocultural transformations in the understanding of madness (ALVERGA; DIMENSTEIN, 2006; AMARANTE; TORRE, 2018), it is a phenomenon still observed as a producer of exclusion.

The concept of stigma gained repercussion with the studies of Goffman (1988). The author developed reflections in which he highlighted stigma as a socially constructed form of pejorative attribution to certain physical or symbolic attributes of people or groups. Since then, it can be approached as an obstacle to the recognition of people's dignity, as the stigmatizing perception tends to depreciate the subjects and emphasize a supposed inferiority of the stigmatized ones.

This social phenomenon should be considered by Collective Health workers and researchers as an important element that permeates the health-disease process. As Monteiro and Vilela (2013) point out, there is a need to address it, examine power relations and the repercussions of stigma on life opportunities and on the health conditions of those who suffer from the problem.

Recognized as a problem to be faced by mental health in health systems, stigma needs to be addressed by public policy makers due to its negative impacts, such as the impediment to the resocialization of subjects and the impairment in the search for mental health care (HENDERSON; EVANS-LACKO; THORNICROFT, 2013; PARKER, 2013; SILVEIRA *et al.*, 2018). Its effects often operate as a condition that produces barriers to free and comprehensive access to care (CORRIGAN; DRUSS; PERLICK, 2014). Furthermore, it negatively affects not only service users, but also the care network, and can even be reproduced by health professionals (VIEIRA; DELGADO, 2021).

In view of the relevance of the problem for the organization of community-based mental health care, it is observed that it is essential to know and build strategies to reduce stigma in the territories. The deinstitutionalization process in the field of mental health policies must have as one of its objectives to seek to transform the relationships that society establishes with madness (ROTELLI, 1990; LIMA *et al.*, 2020).

Andrade and Maluf (2014) have highlighted that, in the national literature, the reform experience has been predominantly discussed from the point of view of workers

and managers. Considering that the formulation of these policies must involve the participation of those who have experienced the experience firsthand, we agree with Cea Madrid (2019): it is necessary to give relevance to the role of social movements of users and family members in the production of knowledge about mental health care.

In the Brazilian scenario, the social movement of the anti-asylum struggle shows itself as one of the movements in the field of defense of Human Rights, which strives for the end of asylums in all its modalities and discourses that produce oppression (LOBOSQUE, 2003). It brings together workers, users and family members of mental health services, who have denounced the violence suffered by people with psychological distress. In this way, it has positioned itself in defense of community services in the Unified Health System (SUS), by defending care in freedom and by seeking to fight stigmas, thus proposing a re-signification of the place of madness in society (BARBOSA; COSTA; MORENO, 2012; AMARANTE; TORRE, 2018).

Considering the influence of this social movement on the reality of the Brazilian health system, and one of its objectives, which is to provide a way to confront the stigma of madness, we asked: How do users and family members who are in the Psychosocial Care Centers (CAPS) and, at the same time, are part of the anti-asylum struggle, experience and face the process of stigmatization in their lives?

In this sense, this work aims to understand the experience of living with the stigma related to mental disorders among CAPS users and family members. This study is part of the research for a doctoral thesis entitled “The persistence of stigma about mental disorders in the experience of users and family members of the anti-asylum movement”.

## Method

### Research type

The methodological option for the qualitative approach, with the construction of a narrative-type research, is due to the fact that it includes personal reports about certain social problems, such as stigma, presenting itself as an important tool for knowledge production in Collective Health. As Castellanos (2014) states, the recognition of the health-disease process as a personal and social experience brought the importance of narratives as a way of understanding the elaboration of such experiences.

Thus, narrative research allows for an analysis that situates the specific context of interaction in the subjects' lives, as well as their social context. As Onocko-Campos and Furtado (2008) state, this methodology provides an analysis exercise aimed at overcoming the dichotomies between macro and micro politics, between individual and social structure, seeking to understand the articulation of these dimensions.

In addition, narrative research has the potential to recover the active voice of subjects who, at times, suffer from the silencing promoted by the subordination imposed by biomedical knowledge, which tend to ignore the subjective experience of the health-disease process and prioritize reductionist and physicalist explanations. As Duarte (2018) states, it is not about proposing a supremacy of knowledge from the Social and Human Sciences, which subsidize narrative understanding, but ensuring the inclusion of equally legitimate explanations about the human experience, which integrate subjectivity and history as belonging to the field of scientificity on the human.

## Participants

We opted for the intentional formation of the group of informants, because, when dealing with psychosocial issues, the performance of a phenomenon, even if oversized in some typical individuals, reveals the context in which they are inserted and can show what similar others experience (FONTAELLA; RICAS; TURATO, 2008).

Users and family members with any gender identity, over 18 years old, residing in the city of Fortaleza and who had been linked to a CAPS for more than a year were included. Another selection criterion was the fact that the participants had political participation in the anti-asylum social movement for at least one year. Users and family members were personally invited to a face-to-face meeting of the movement when the research was presented to them.

We had the consent and interest of the seven members of the segment of users and family members of the core of the anti-asylum movement, of which four were users (two men and two women) and three were family members (two women and one man). The age range of the group varied between a minimum age of 31 years and a maximum of 72 years. Among the users, all had been diagnosed with severe mental disorders. In the case of family members, the three were responsible for accompanying the ones with the same diagnostic condition.

It is also worth noting that the group has had active participation since 2012, when most joined the movement as a result of a workshop held on the protagonism

of users and family members in the city. Among those interviewed, some users are retired due to their condition and family members have informal jobs or precarious work relationships. All interviewees have already taken part, and some still do, in committees and social participation councils of the SUS.

### **Tools for information production**

In-depth interviews were carried out with the members based on a script with two themes pre-established by the researchers based on the evidence of the identity effects of the mental disorder diagnosis. Participants were asked to tell their life stories since seeking mental health services and to report whether they had ever suffered any type of discrimination. The interviews were carried out individually in reserved rooms at the university between March and November 2019.

### **Analysis procedures**

For information analysis, we chose the dialectical hermeneutic analysis proposal (MINAYO, 2013). This choice is due to the potential of the proposal to indicate an interpretation of the phenomenon from its subjective representations, considering its dynamic relations with the historical, social and political context.

Speeches were recorded in audio and transcribed in a text editor. A reading was carried out to reveal the meaning and interpretations of the subjects about their experiences. After this procedure, empirical categories were created to order the information produced by the narratives. Representative narrative segments of key moments for the interviewees were highlighted.

Four key moments were listed in the narrated experiences: in the first moment, experiences of stigma in daily life stand out; in the second, the interviewees report the resignification of stigma on mental health services; in the third moment, they count on the positive reframing of their identities with the discovery and valorization of potentials; and, finally, expose the confrontation with stigma and political engagement in the anti-asylum struggle.

Goffman's (1988) theoretical framework on the issue of stigma and contemporary studies on this topic were tools for the dialogue between the knowledge brought by the narratives and scientific production. In this way, the empirical categories, created from the narratives, were compared and contrasted with the theoretical reflection and with the social historical context.

This work complied with the determinations of Resolution 466/2012 of the National Health Council. It was submitted to an ethics committee at Plataforma Brasil and approved with CAAE: 25089819.4.0000.5534. All participants were informed about the research objectives with the reading and presentation of the free and informed consent form. The identification of the interviewees was kept confidential, being named with the order number in which they were interviewed (Interviewee 1, Interviewee 2, ..., Interviewee 7).

## Results and Discussion

### Experiencing stigma in everyday life and avoiding discredit

Since the beginning of their experiences, the interviewees reported that they realized that their condition would be the target of public discrimination. Such perception made them build forms of concealment and protection of their identities in coexistence with others.

I went to the pharmacy to buy medication. Because sometimes it was passed to buy, and I was ashamed. I would go to another pharmacy that was not in my neighborhood to buy it. Because I thought the woman would see me, you understand? That she was going to say that I was crazy, that I was from the CAPS... I went out hiding from the neighbors. He didn't say where he was going. (Interviewee 1)

The feeling of insecurity for being recognized as a CAPS user, observed in the narrative of Interviewee 1, is one of the aspects pointed out by Goffman (1988) as a generator of anxiety and tension in interpersonal relationships among those who suffer from stigmatization, due to the fear of suffering with disrespect. It was identified that the visibility of the disorder, due to the relationship established with the psychotropic medication, brings social information that can be perceived as a “symbol of stigma”. Stigma symbols are social symbols that activate a perception of discredit and inferiority of the subjects who possess them (GOFFMAN, 1988). That is, the medication could be identified as a mark of defect or disadvantage, which causes initial discomfort in the social interaction circles of Interviewee 1, who tries to cover up this information.

Considering the contemporary context in which medicalization has become common in our society, it is clear that, even so, the subversion of the precepts of the rational, self-controlled and productive subject, as in the case of people who use psychiatric medications, produce and feed back in social interactions the meaning of mental disorder as weakness and disadvantage (CAPONI; DARÉ, 2020).

The fear of being disrespected and attempts at concealment are based on the experiences of the interviewees. The reported stories show recurrent discrimination not only in the territory, but also within the groups of friends and the families themselves, as seen in the narrative of Interviewee 5, as follows:

I suffered exclusion from some friends. They called me crazy. They said I had gone crazy. Family members also excluded me. When I arrived at the house of a relative of mine, they had that different look, of fear. A sister-in-law of mine advised my wife to separate from me. It was cruel. (Interviewee 5)

The literature shows us that this fear and rejection of madness identified by the interviewee's relatives are elements that have become present in different cultures since ancient times (BLEICHER, 2016). Given the report, we can infer that normative expectations still circulate and tend to seek to confirm the identity of the person with a mental disorder based on an image of the bizarre, the dangerous and the threatening, generating fear and the need for exclusionary social distancing. The lack of initial acceptance by Interviewee 5's friends and family ends up producing and intensifying a sense of disbelief and helplessness, which can contribute to the internalization of the stigma, as stated by Nascimento and Leão (2019).

In other situations, as in the excerpt below, the family's difficulty in recognizing the suffering experience of the person with a mental disorder was also evident.

When I started with depression, I saw myself a lot like this, down. Because my family never supported me, you know? It was like that all my life, of people thinking I was being silly. That there was nothing. Then, when I got sick, with these problems, they started taking me to the neurologist. I started to "bump electros" in my head. I knocked several times and it was just normal. Then the doctor said: No, she has no problem! Her problem is just "nerve". (Interviewee 4)

It is seen in the experience of Interviewee 4, as already pointed out by Guimarães and Meneghel (2003), that mental suffering is disqualified as if it were minor compared to other health problems or is not even considered a disease, as it does not fit the explanatory model of biomedicine.

Since it appeared in the speech of a woman, we see the need to think of this process of stigmatization as crossed, also, by the relations that produce inequality between the genders. Because it is not an isolated case, and other studies show this recurrent treatment (ZANELLO; FIÚZA; COSTA, 2015), we found a tendency to make suffering invisible, which turns into a disqualification of the woman herself.

With regard to the interviewed family members who care for and accompany relatives in mental health services, there were reports of concealment or overprotection, seeking to prevent their loved ones from being the target of possible constraints:

I've seen people who had like a meltdown on the bus. But people don't have an understanding and don't know how to face it. [...] In the case of my mother, with her it doesn't happen so much. Because I'm very careful with her. Where she goes, I follow. There was a time when she wouldn't go anywhere alone. (Interviewee 2)

After my mother came back [from being admitted to a psychiatric hospital], she didn't walk for a long time, without going to a bakery. Even my own sister, just not to allow it... To avoid such conversations. My sister spared my mother a lot in this process. This is very bad. (Interviewee 6)

The woman at home doesn't want me to keep saying that my son is a user of the service. Because he is finishing college and wants to get a job. She says: don't keep saying that your son is a CAPS user! Because when the guy goes looking for a job, people will find out about it. (Interviewee 7)

It is understood, from the statements of Interviewees 2, 6 and 7, that the reaction of family members is a defensive strategy to seek to circumvent the excluding effects of the persistence of stigma in the daily lives of their loved ones. This concern is based on the reality perceived by them, but is also shown by Nunes and Torrente (2009), who already identified numerous situations of violence suffered by users assisted by the CAPS in the territory where they lived. At the same time, it is observed that there is a fine line between care and guardianship in the attitudes of family caregivers. This line becomes problematic with the imposition of limits to the freedom of family members, encouraging possible new processes of user exclusion.

The concern of family members, as in the case of the wife of Interviewee 7 in trying to keep the child's condition confidential, is not detached from reality. As pointed out by Mascayano *et al.* (2016), the stigma associated with the mental disorder can reduce contacts with social support networks and, consequently, lead to a decrease in opportunities, including indications and possibilities of insertion in the labor market.

Regarding the passage of the relative of Interviewee 6 through the psychiatric hospital, what Goffman (2013) pointed out is confirmed: this is a decisive experience that marks the moral career of the subjects. Hospitalization becomes incorporated as a remarkable event in people's biography and their lives can be interpreted from the perspective of psychiatry knowledge. The attempt to protect family members



seeks to mitigate the suffering of discrimination resulting from this event, even if this overprotection is perceived as a bad solution.

It should be noted that, in the case of Interviewee 2, who has a family member who undergoes her treatment in the community service, that she is also afraid of stigmatization. This shows that stigma operates as a social relationship and is not restricted to a single social facility. This finding leads us to confirm the need to think about deinstitutionalization as a complex process that must act on the collective imagination. Thus, as stated by Palacios-Espinoza (2021), it is necessary to create structures and interventions in the community that can prevent the process of stigmatization, promoting reflective and supportive behaviors of coexistence with human differences.

This same fear of being pejoratively labeled was brought up by Interviewee 3, who spoke of a time when he tried to dodge a neighbor to try to cover up the fact that he was undergoing treatment for his mental health.

I had forgotten my SUS card. My wife said, already on the street, outside the house: Look, take your SUS card. If not, you will arrive at the CAPS and you will not receive your medicine. My neighbor listened and said: Do you receive treatment at the CAPS? I was like that, I stopped talking. [...] I do, what's the problem? He said: You know it's a crazy place there, right? No, what would be crazy for you? I also had to chat with him. (Interviewee 3)

It is thus observed that there is a dynamic of manipulation of identity to try to cover up certain stigmatizing attributes, which is a constant issue in the lives of stigmatized people, as observed by Goffman (1988).

Interviewee 3, however, shows that the subjects are not passive in the face of discrimination and try to face discredit and the attempt to demean their identity through dialogue. This situation shows that, although the phenomenon of stigma persists in society, there is also a dispute over the affirmation of the condition of a new place for madness, brought about by the ideas disseminated by the Anti-asylum Psychiatric Reform (AMARANTE; TORRE, 2018). Thus, new ways of understanding the phenomenon of madness and mental suffering are introduced into the culture.

These conditions seem to point to a new form of reaction by the stigmatized, arising from this new paradigm of thinking about mental health policy as intended to promote users as subjects of rights (NUNES *et al.*, 2011; BLEICHER, 2019) and not as objects for intervention of specialized knowledge.

## Resignifying the stigma about mental health services from the CAPS

Stigma on mental disorders extends to mental health care institutions and professionals who deal with the public in question, since, as identified by Goffman (1988), discredit tends to be shared in a kind of tendency to diffusion of stigma. Faced with this reality, Pinchuk *et al.* (2021) identify that stigmatization is one of the factors that strengthen the problem of the mental health care gap by producing refusal and delay in people seeking help.

This is evidenced by the reports that, initially, some users and family members had negative perceptions about the services. However, the narratives show an outcome in which there is a transformation of this view due to the way they were welcomed.

I knew CAPS existed. But I thought it was crazy people who were there. When I went there, I was also prejudiced. What am I doing here? What am I going to do here? I'm not crazy! [...]. Today, I make a point of talking about CAPS to people close to me, friends... I defend where I walk, you know? (Interviewee 1)

Because I had a vision of CAPS as if it were like a madhouse. As if I got there, they were going to give me an injection to calm me down and I was going to stay there in a closed environment [...]. When I saw that people received me wonderfully, with all the attention, they were super polite, then I felt good in the space. (Interviewee 3)

That's when we became aware of the substitute services, which is the CAPS. And that's when I started to get better. I felt the difference from the hospital right on the first day, in the welcome, where people listened to me. For me, listening is better than any psychotropic. (Interviewee 5)

Some family members reported that their relatives also had pejorative views about CAPS. In the case of Interviewee 4, family members tried to convince her not to seek the service. However, she mentions that, due to the anguish of finding a solution to her suffering, she did not feel intimidated in seeking help.

I said at home that I was going to the CAPS. They "thickened" [expressed opposition]. I said: I don't want to hear about conversation! Because [family members] said that CAPS was a crazy place. That I wasn't crazy, I don't know what. I don't want to hear about the conversation. I'm going there and that's it! (Interviewee 4)

As socialized beings within this reality where the mental disorder is stigmatized, it would not be surprising that users and family members could keep, in their way of seeing, a derogatory view of services. As Berger and Luckmann (2005) state, the interiorization of reality is not autonomous, but takes place from what is already pre-defined by social institutions, which bring motivational and interpretative schemes about it.

It is observed, however, that users and family members found in the CAPS a starting point for re-signification about the way of caring for mental health, based on the differentiated reception of the service. In this context, where we have been living with questions and attacks on the Psychiatric Reform and its historical achievements (CRUZ; GONÇALVES; DELGADO, 2020) such as the implementation of CAPS throughout the Brazilian territory, the potential of this care device is perceptible, which, even though it is precarious and underfunded, shows signs of its potential.

It is demonstrated, with the examples reported by users, that, from the CAPS, emancipatory care can be offered (BARROS, 2021). This proposal, by pointing to a process that privileges the production of new forms of relationship, promotes the development of autonomy and the redefinition of the role of users and family members, pointing to the emancipation of traditionally produced forms of subjection and positively impacting the lives of the people served.

### **Reframing themselves and discovering potentials**

The work process developed at the CAPS showed, as observed in the interviews, a potential to transform the stigmatized view of both the service and the user about himself. This process, which occurs throughout mental health care and acts to minimize stigma and recover a positive image of oneself, produces recognition, or discovery, of potential by mental health professionals. This was shown in the report of Interviewee 4 when talking about the perspective of a professional about skills that already existed in her life before becoming a CAPS user.

When I said what I knew how to do [handicrafts, sewing], I was taught there for the others. Dr. Occupational Therapist X went and said, 'My God! You came in here, you're doing this therapy and you already know how to do all this?'. I say yes'. 'And who did you learn from?' I said: 'I learned from no one. It was just God's thing. [...] Then, now, because I have this support from many people, living with people from the social movement, people that I see, that I really feel that they value me, admire me for many things that I do, I feel like another person. Another person indeed! (Interviewee 4)

In the case of Interviewee 5, the awakening to artistic talent, through incentive and training activities for the visual arts within the service, also mobilized the possibility of elaborating and denouncing his opposition to treatment in the psychiatric hospital.

That's when I got to know CAPS and they discovered my artistic talent. And, to this day, I do all my works to show the importance of art in mental health. I fight to show people

that mental health is not done in an asylum. And with freedom, with love, with art and with listening. (Interviewee 5)

We noticed that the CAPS returns users to the territories where they live through the exhibition of the works carried out, but now showing the power of subjects who were previously seen exclusively with the identity of diagnosed and are now recognized as artists and craftsmen.

The fact of finding a service where they are respected and recognized as subjects produces a greater approximation and an interest that goes beyond the frequency in search of professional consultations and medication, as indicated by Interviewee 2 in the following excerpt:

In the beginning, when my mother started to be treated, I went only as a user. Ah, today is the day of the appointment, I'm going to the appointment. But when I started to see the need, starting to get to know the CAPS, I started to get interested in it. I became friends with people. They called me to participate in that, in that other thing. Then I became interested and stayed. And I am to this day. (Interviewee 2)

Interviewee 7 also reports his feelings of gratitude that mobilize a retribution action.

I am very grateful to CAPS. It was a concrete gesture they made with us. My son has a healthy life. He is just like us [...]. I worked at CAPS as a volunteer. I was a mental health volunteer. In this joke I worked more than 12 years there. I was a community therapist. (Interviewee 7)

The bond between family members and mental health service professionals suggests a decrease in perceived stigma about services and also shows how important the involvement of family members is in addition to follow-up in consultations. These observations are supported by studies on the participation of family members, which show the need to invest in relationships between family members and professionals (MARTINS; GUANAES-LORENZI, 2016), even acting in the production of greater co-responsibility of family members (CARVALHO *et al.*, 2020), as the narratives of Interviewees 2 and 7 illustrate with their voluntary engagement in service activities.

It can be seen that, by taking part in voluntary and social control activities at the service, these activities begin to act as stigma mitigators and provide, as stated by Gemelli and Ultramari (2020), a social recognition that collaborates in the positive construction of their identities. This principle of strengthening the recovery of people

with mental disorders from a singular point of view and, at the same time, aimed at promoting the subjects' potential is an important factor in reducing stigmas.

### **Facing stigma and engaging politically in the anti-asylum struggle**

The new relationship established with mental health services, aimed at empowering and encouraging subjects to participate, ends up also fostering processes of resistance to stigma and discrimination, as we can see in the statements below:

Sometimes I talk to someone in the waiting room. I start talking about the service. Are you from here? Are you patient? I am. Long time. I am delighted to say that I am. To break that stigma. Because they themselves have it with them. (Interviewee 1)

I always fight against this prejudice of people. I always try to clarify, inform. Because I see a lot of people who are uninformed. That there are even people in the family who need it and don't know about it. (Interviewee 3)

The empowerment process ends up linking the subjects to other institutions, both the formal deliberative organizations of the health councils and the movements that fight for rights. These links promote a change in self-perception and, at the same time, make up a movement to produce another image of mental illness beyond the stigmatized and deficient one current in society, as stated by Soalheiro (2012). It is seen that many began their participation in the anti-asylum movement as a way to expand their activities in defense of humanized care.

There, that's it. I started to fight in Council. They put me on to represent the CISM [Mental Health Intersectoral Commission of the State Health Council]. I'm still in there until today and I feel very good, thank God. (Interviewee 4)

That's when I found out about the anti-asylum struggle movement. I understood that there was a struggle for this. When I joined the anti-asylum struggle, I was very touched.... Today I can talk about it. I joined the anti-asylum struggle in 2017. On May 18, 2017, I was already there [in a public act]. In that period, it was a period of many tears. Every time I talked about it, I cried. It was in March 2018 that I started talking about what my mother went through [in the psychiatric hospital]. (Interviewee 6)

I tell a little of my story of what I suffered in asylums and I say why I fight. I am militant today to prevent other people from going through what I went through. Despite the setback that is there. We know that there is still a lot of suffering in hospitals [...]. I say that today I am part of the anti-asylum movement, which I am a member of. The movement helped me a lot. I learned a lot about mental health. (Interviewee 5)

It was during this period of this trajectory that I went through that I met So-and-So (member of the movement). I walked a lot with Mr. So-and-So in CISM, in the State Council. It's where I grew up. I participate and they love me very much. Today I am part of the anti-asylum family. (Interviewee 7)

It is observed that political participation emerges as a need to denounce the suffering experienced with family members in psychiatric hospitals, as in the case of Interviewees 5 and 6. Cea Madrid (2019) also observed, in another group of users, the need for organization around the defense of rights that arises after episodes of violence and mistreatment in mental health services. It is precisely this collective organization that makes it possible to stress public policies and services for the recognition of users and family members as subjects of rights, besides highlighting the need to eradicate negative stereotypes and to value the experience of those who experience the care they receive.

It is also seen that new relationships established with social control and with existing social movements in the city emerge. Thus, the interviewees show the need for people with mental disorders to be treated, as Soalheiro (2012) points out, as social agents and political subjects. It is evident that engagement in the anti-asylum movement and in the councils enables a reformulation of the stigmatized identities of people with mental disorders and their families through the construction of the image of active subjects of rights in the proposition of reformulation and evaluation of the mental health policy in its local context.

As indicated by Andrade and Maluf (2014), for many of these users and their families, the psychiatric reform enabled the expansion of participation in public and political spaces, where people can make their voices heard and express their desires. Such engagement does not push them away, or make them deny, the treatments received by professionals, but it seems to change the relationship between professionals and the service. Vasconcelos (2000) even highlights the emergence of international movements that build self-help groups, clubs and services run by users and former users. Now, a trend of the user, or family member, is no longer seen as someone who passively obeys professional prescriptions, but as someone who negotiates, redefines their own expectations about themselves and rejects the assumed identity of inferiority and subalternity attributed to people with mental disorders.

## Final remarks

The experience of users and family members of mental health services, when living with the stigma of mental disorders that still persists in society, attests the importance of institutional strategies to face this situation. It is noticed that, even

in the midst of the limits and difficulties faced, the CAPS reveal a potential for transforming people's lives by rescuing their potential and recognition as political subjects through their care practices. This equipment and its workers thus contribute as a fundamental element in the process of overcoming the stigma of mental disorders and in promoting a different perspective of society on madness.<sup>1</sup>

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## Note

<sup>1</sup> R. R. Pires: conception, design, analysis and data interpretation. A. B. de Alencar and A. R. Ferreira Júnior: writing of the article, relevant critical review of the intellectual content, approval of the final version to be published. J. J. C. Sampaio: design, analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content, approval of the final version to be published.

## Resumo

### *O cuidado em saúde mental e a participação política de usuários e familiares na resignificação do estigma sobre os transtornos mentais*

A persistência do estigma associado aos transtornos mentais deve ser um problema a ser enfrentado pelos sistemas de saúde na luta contra a discriminação de pessoas que experienciam sofrimento psíquico. Este estudo qualitativo, do tipo narrativo, objetiva compreender a experiência de conviver com o estigma relacionado aos transtornos mentais a partir dos relatos de usuários e de familiares de pessoas atendidas em Centros de Atenção Psicossocial de diferentes regiões da cidade de Fortaleza-CE. Foram entrevistados quatro usuários e três familiares que guardavam a particularidade de pertencerem a um núcleo da luta antimanicomial. Por meio de um roteiro com perguntas sobre as experiências individuais na busca por cuidados, as informações produzidas foram analisadas pelo método da hermenêutica dialética. Os resultados mostram que o estigma se faz presente no cotidiano, implicando sofrimento e discriminação. Contudo, os processos de cuidado recebidos, orientados para o reconhecimento dos potenciais e da condição de sujeitos políticos, resignificaram percepções negativas sobre si mesmos e sobre os serviços em que eram atendidos. Esse processo colaborou com o engajamento dos usuários e dos familiares nas instâncias oficiais de controle social e no movimento antimanicomial, instigando, entre os sujeitos, a defesa do cuidado humanizado e do combate ao estigma.

► **Palavras-chave:** Estigma social. Transtornos mentais. Saúde mental. Narrativa pessoal.

