



Between challenges and possible openings: life in freedom in the context of the Brazilian deinstitutionalization

Entre desafios e aberturas possíveis: vida em liberdade no
contexto da desinstitucionalização brasileira


Maria Inês Badaró Moreira^a

 <http://orcid.org/0000-0001-5798-2023>
E-mail: mibadaro@gmail.com

André Vinicius Pires Guerrero^b

 <https://orcid.org/0000-0001-7240-1506>
E-mail: andre.guerrero@focruz.br

Enrique Araújo Bessoni^{a,b}

 <https://orcid.org/0000-0003-0521-1627>
E-mail: eabessoni@gmail.com

^aUniversidade Federal de São Paulo. Santos, SP, Brasil.

^bFundação Oswaldo Cruz. Brasília, DF, Brasil.

The current context of mental health care in Brazil indicates significant risks and losses towards care in freedom. The design of the psychosocial care network is being weakened with consequent reinforcement of a hospital-centered care model, which has already been considered as iatrogenic and exclusionary. At this moment of evident setbacks, we present this dossier in defense of deinstitutionalization by uncovering the lives of people who had been interned for many years and began to live in freedom, supported by strategies such as those included in the De Volta para Casa Program (PVC - Back Home Program). In addition, it is regarded as a political stance of a group of researchers who understand the challenges in their constitution and implementation, who above all believe in the right to freedom, housing and community life as supportive and confrontation community elements for currently taking care of severe psychic suffering.

The PVC is part of the deinstitutionalization strategies, created from innovative and avant-garde municipal experiences. It took a long democratic process of discussion that reached consensus in four national mental health conferences about the direction of the Brazilian Psychiatric Reform, these strategies were expanded, with their own budgets and funding that gave the Brazilian reformist process international recognition. There is important literature before and after the promulgation of Law 10.216/2001 (Brazil, 2001) with fundamental syntheses about the expansion process, including policy hindrances, given the ongoing process setbacks. (Amarante; Nunes, 2018; Delgado, 2011; Pitta, 2011; Tenório, 2002).

Correspondence

Maria Inês Badaró Moreira
Rua Silva Jardim, 136, Vila Matias. Santos, SP, Brasil. CEP 11015-000.

This literature points to some issues always present during the reform period, especially considering the period of proceduring. It is known that the project took more than 10 years to be approved in the Brazilian National Congress, which happened in 2001 through a window of opportunity, when Brazil was able to take a sanctioned law as a contribution to the thematic discussion on mental health proposed for that year in the meeting of the World Health Organization (Delgado, 2011).

This process was submitted for changes and revision, which, according to the author, would be a reassessment of the fundamental precepts that constituted the initial concept of the reform, but the law kept preserving the idea of the struggle for a society without asylums. This motto arrived in Brazil in the late 1970s with the experience of Franco Basaglia (1982), who demonstrated, in different ways, the possibility of understanding and living with the experience of madness in its complexity, in a manner that opposed simplifying diagnostic and biomedical views of this phenomenon. Based on these precepts, the required deinstitutionalization also pointed to the removal of the search for treatment/cure in isolation, and defended a place for coexistence, exchanges, protagonism of people, the exercise of citizenship and free circulation in the city.

Therefore, and according to Delgado (2011), the application of legal precepts based on the public policy for mental health implemented in the Brazil, since its origin, demanded continuous monitoring in order to defend and protect the rights of people in psychic suffering, from the legal point of view. Also evident was the need to recognize the role of patients, family and society as protagonists in the constant struggle to consolidate the Brazilian Psychiatric Reform.

Similarly, Amarante and Nunes (2018) recognize, in the history of Psychiatric Reform, the important action of social movements to guarantee the rights of people in psychic suffering. Specifically, they note that the lemma "For a society without asylums" establishes, since the 1988 Bauru Meeting, two significant transformations. The first would be its constitution, as it incorporates, in addition to workers, users, family members and human rights activists. The second transformation occurred with

the expansion of the initial claims to improve the system in order to struggle against any situation of oppression, especially a constant struggle against the violation of the rights of people in psychic suffering, and not only of those who were hospitalized in psychiatric hospitals. This was the foundation of the National Anti-Asylum Struggle in Brazil and the broadening of its social visibility.

In addition, it is worth highlighting the expansion of the network of substitutive and community services that was structured and intensified in the 1990s with the reallocation of resources previously and exclusively destined to psychiatric hospitals. Different experiences have contributed to the regulamentation of a wide psychosocial care network with diverse community services ensuring care in attention to freedom (Tenório, 2002). Since the 1990s until 2015, the Ministry of Health (MS) issued periodic reports presenting the expansion of services and actions in mental health and highlighting increases in the provision of services - with 198 Psychosocial Care Centers, in 1998, which expanded to more than 2,400 services in 2014 - added to the implementation of different equipment, services and network actions in municipalities of all regions. In addition to this type of service, we highlight the Family Health Support Centers (Nasf), the teams of street offices, the temporary residences, the therapeutic residential services, the temporary care units and the offering of beds in general hospitals, which became part of the Psychosocial Care Network (Raps) (Brazil, 2016).

Since the tense change of the mental health coordinator in December 2016, the MS has been imposing evident setbacks in public health by assuming a conservative and neoliberal perspective. In recent years there has been a weakening of public services, with the reallocation of resources to a model focused on hospitalization and isolation: this means the return of the asylum model. This setback, sanctioned by several ordinances, was widely disclosed by reports of the time. In response to this damaging involution, we point to a fundamental analysis in the editorial of a Brazilian national newspaper. Signed by the former mental health coordinators Domingos Sávio Alves, Pedro Gabriel Delgado and Roberto Tykanori (2017), and

subscribed by Eliane Maria Fleury Seidl, Alfredo Schechtman, Ana Maria Fernandes Pitta and Leon Garcia, this text rescues the Brazilian Psychiatric Reform, by presenting data and process gains, and denouncing the imposition of setbacks by the new administration. The article highlights the popular participation in the agreement of the Brazilian National Policy guidelines as well as the expansion and creation of new services, reinforcing the origin of the movement aligned with the redemocratization process of Brazil. On the other hand, it emphasizes how the MS resumed investments in asylums, hospitalizations in therapeutic communities and the return of mental health first-aid rooms. The editorial finished with the Federal Prosecutor's Office of the Citizen's Rights and National Human Rights Council questioning of this alarming redefinition of service priorities and its consequent reorientation of resources, and yet the MS has remained on this path.

This contextualization was necessary to resume the importance of the guidance made by Law nº 10.216/2001 as well as the guidelines agreed upon the national mental health conferences, by affirming that it is possible to build a society without asylums and to defend that freedom is therapeutic. This is the defense of the deinstitutionalization process so far conducted in Brazil.

These actions echo in Venturini's (2016) reflections about the different meanings for the word "deinstitutionalization". According to the author, the deinstitutionalization process refers to a change in the conception of what is really understood by the so-called "mental illness". He proposes dimensionalities for a deinstitutionalizing action, in which there are open questions about madness, the social apparatus created around it, the hegemonic way of conducting mental health and even the psychiatric knowledge that is extended to many varied professions.

The author starts from an intervention he conducted in Imola, in which he proposes to put into perspective all the transpositions that took place in Italy and the other experiences carried out, having the city of Trieste as inspiration. The transversality of these experiences leads to the conclusion that chronicity is a reflection of the development of strategies implemented in the exclusionary hospital world. Recognizing the

complexity of a deinstitutionalization process, he warns of its different conceptions, ranging from a symbolic revolution to the exercise of citizenship rights. Actions that necessarily go through a set of administrative, technical initiatives: sometimes a paradigmatic reference from the health field, sometimes from the field of anthropology (Venturini, 2016).

Given the current Brazilian reality, Delgado (2019) emphasizes that we must look at the dismantling of a paradigm shift process that has been taking place in Brazil since 2016, confirming the ongoing neoliberal agenda. The author lists the measures taken during this period: the dismissal of community agents in family health teams; readjusting of psychiatric hospitalization rates, increasing of funding; the reduction in registrations of new Psychosocial Care Centers, the stimulation of open vacancies in therapeutic communities, the resuming of the hospital-centered model, the readoption of the obsolete day hospital and restructuring of specialized outpatient health care model disconnected from territorial demands. In this way, he calls for resistance in all frontier spaces and brings together the forces of the social movements, professionals involved with health services, allies, students, users and family members. And so we followed attentive and united to the trenches.

This dossier presents different perspectives on the PVC, resulting from a national research coordinated by Fiocruz/Brasília, with the authorial participation of researchers from the Universidade Federal de São Paulo (Unifesp - Baixada Santista), Universidade Federal do Rio de Janeiro (UFRJ), Universidade Federal do Sul da Bahia (UFSB), Universidade de Brasília (UnB) and Instituto Philippe Pinel, which aimed at evaluating the role of PVC by means of the report/life history of people with a long history of hospitalizations and also regarding the deinstitutionalization process within the Brazilian Psychiatric Reform. Researchers from the Universidade Federal de Pernambuco (UFPE) and the Universidade Federal de Campina Grande (UFCG) also participated.

These reflections are from researchers from different public institutions that focused on the theme in a multicentered national survey conducted

in different states, in order to seek nuances that represent the Brazilian reality in the lives of patients. Accordingly, these researches reflect the diversity of the researchers' views, the exercise of collective reflection over the findings, the multiplicity of related existential territories and also the challenges faced at the moment of evident setback of the public policy that guarantees the precepts of care with freedom. Thus, the following articles are designed as proposed by the researchers.

The article "De Volta para Casa Program (Back Home Program) in its beneficiaries' daily lives" presents the results of evaluative research about its effects on the process of social reintegration. It indicates that the PVC has been playing an important role in redirecting mental health care in Brazil, starting from Law 10.216/2001, which consists in facilitating assistance for the broad process of deinstitutionalization and social reintegration of its beneficiaries. Research conducted in several states used multiple methodological approaches including document analysis, interviews with key program implementers, beneficiaries' life itineraries analysis, day-to-day observations, and a research monitoring committee composed of beneficiaries, workers and representatives of the local community. At the end of the study, narratives were elaborated through participant observation, informal conversations and interviews. The results from these data presents challenges to the construction of affective networks and psychosocial support, concluding the advances of this policy to the lives of beneficiaries with guaranteed contractual power in the context of the Brazilian Psychiatric Reform.

The article "Shared knowledge production in mental health: the Research Monitoring Committee" conceptually presents the research monitoring committee (CAP) as an instrument, its conception and its use in health research, reflecting on the use of this methodological tool in the research evaluation of the PVC. It analyzes its contribution to participatory evaluative research and the different ways in which it occurred, considering the peculiarities of each research territory of research. This methodological tool is advocated for promoting the participation and protagonism of the people involved in the study, as

well as ensuring space for knowledge sharing about health policies in general.

The use of narratives in a slow and affective construction is presented in the article "Building stories in slow tessitura: deinstitutionalization and narratives in research". The authors start from criticisms of the asylum model and the redirection of the public policy of mental health care that enabled the construction of actions in an ethical-political mode of care, based on the Brazilian Psychiatric Reform. They bring up studies and perspectives on the challenges of care in freedom and the production of knowledge arising from it, in addition to narratives used in evaluative multicenter research on the impact on beneficiaries' lives for 15 years of the PVC, residents of 11 Brazilian municipalities. The theoretical-practical referential on the deinstitutionalization used highlights the importance of this meeting as a texture among information, stories and affections in the meetings between beneficiary and researcher for the production of narratives. The authors also bring contradictions that emerged in the course of the research and defend the maintenance of this dialogical and relational encounter as another way to ensure the recognition of themselves and others in the authorship of life in composition with the social texture.

In the article "Narratives and senses of the De Volta para Casa Program (Back Home Program): we are back, and now what?" international and national studies on the impact of public policies, as well as the beneficiary's own assessment of them are presented, bringing findings regarding the repercussion of PVC in the existential territories, and in their beneficiaries life's itineraries. It lists four primordial elements: life history, autonomy, what money has done and does now, and relationship with the health network. These data revealed a profile of people mostly in socioeconomic vulnerability, predominantly of black color and with low education. The history of exclusion and neglect of these social groups would have contributed to the illness, seclusion and permanence in closed institutions. The study provides relevant data that contribute to a look at the ways of living and the process of deinstitutionalization, with increased contractual

power regarding self-care, and the establishment of affective relationships, while moving around the city. Finally, it points to the possibility of opening new social and affective dimensions arising from the opportunity of living in and belonging to the city.

The article “The net is cast and the management rhythm snags” reveals the delicate report of experience carried out by the researcher during her postdoctoral internship. It analyzes the real time living of the events surrounding the PVC research in the context of the setback of the public mental healthcare policy, in the light of an experience that precedes such events. It reveals two distinct moments: that of the implantation and structuring of the service network based on the Psychiatric Reform regulations, the PVC and the expansion of the care network in freedom, dialoguing with the implementation of the program and the Therapeutic Residential Service. It also discusses the attempt of a co-management agreement with the Charitable Foundation and the current moment, with the return to the same spaces to carry out the study with the beneficiaries of the PVC. These are intense notes of situations experienced by the author, who seeks a new view 15 years after.

With this set of articles, we convey the wish that the utopia of a reality already lived by thousands of people will be assured by the network of open services that is definitely a substitute for hospitalization. We confirm that the data already reveal the strengthening of the policy and the conquest of citizenship as a possibility of existing. We also want to guarantee a space for the defense of life in freedom for all people and, above all, to call everyone into Franco Basaglia’s claim for freedom to be therapeutic!

References

- ALVES, D. S.; DELGADO, P. G.; TYKANORI, R. Retrocesso na saúde mental? *Folha de S.Paulo*, São Paulo, 14 dez. 2017. Opinião. Disponível em: <<https://bit.ly/2I2zzaa>>. Acesso em: 9 maio 2019.
- AMARANTE, P.; NUNES, M. O. A reforma psiquiátrica no SUS e a luta por uma sociedade sem manicômios. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 23, n. 6, p. 2067-2074, 2018.
- Disponível em: <<https://bit.ly/2K6hB8P>>. Acesso em: 9 maio 2019.
- BASAGLIA, F. *A psiquiatria alternativa: contra o pessimismo da razão, o otimismo da prática: conferências no Brasil*. São Paulo: Brasil Debates, 1982.
- BRASIL. Ministério da Saúde. Lei nº 10.216, de 6 de abril de 2001. Dispõe sobre a proteção e os direitos das pessoas portadoras de transtornos mentais e redireciona o modelo assistencial em saúde mental. *Diário Oficial da União*, Brasília, DF, 9 abr. 2001. Seção 1, p. 2.
- BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas e Estratégicas. Coordenação Geral de Saúde Mental, Álcool e Outras Drogas. *Saúde mental no SUS: cuidado em liberdade, defesa de direitos e rede de atenção psicossocial: relatório de gestão 2011-2015*. Brasília, DF: SAS, 2016.
- DELGADO, P. G. Saúde mental e direitos humanos: 10 anos da Lei 10.2016/2001. *Arquivos Brasileiros de Psicologia*, Rio de Janeiro, v. 63, n. 2, p. 1-121, 2011. Disponível em: <<https://bit.ly/2MvHINX>>. Acesso em: 9 maio 2019.
- DELGADO, P. G. Reforma psiquiátrica: estratégias para resistir ao desmonte. *Trabalho, Educação e Saúde*, Rio de Janeiro, v. 17, n. 2, p. 1-4, 2019. Disponível em: <<https://bit.ly/2I3TrKg>>. Acesso em: 9 maio 2019.
- PITTA, A. Um balanço da reforma psiquiátrica brasileira: instituições, atores e políticas. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 16, n. 12, p. 4579-4589, 2011.
- TENÓRIO, F. Reforma psiquiátrica brasileira da década de 1980 aos dias atuais: história e conceitos. *História, Ciências, Saúde*, Rio de Janeiro, v. 9, n. 1, p. 25-59, 2002.
- VENTURINI, E. *A linha curva: o espaço e o tempo da desinstitucionalização*. Rio de Janeiro: Fiocruz, 2016.

Received: 05/14/2019

Accepted: 06/04/2019

ERRATUM

In the introduction “Entre desafios e aberturas possíveis: vida em liberdade no contexto da desinstitucionalização brasileira”, doi 10.1590/S0104-12902019000003, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ

In the article “O Programa de Volta para Casa na vida cotidiana dos seus beneficiários”, doi 10.1590/S0104-12902019190435, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ

In the article “Produção compartilhada de conhecimentos em saúde mental: o Comitê de Acompanhamento de Pesquisa”, doi 10.1590/S0104-129020190436, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ

In the article “Construindo histórias em tessitura lenta: desinstitucionalização e narrativas em pesquisa”, doi 10.1590/S0104-129020190428, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ

In the article “Narrativas e sentidos do Programa de Volta para Casa: voltamos, e daí?”, doi 10.1590/S0104-12902019190429, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ

In the article “A rede embala e o ritmo da gestão embola”, doi 10.1590/S0104-12902019190443, published in volume 28, number 3, 2019, the section is incorrect.

Instead of:

ARTIGOS

Should read:

DOSSIÊ