

# De Volta para Casa Program (Back Home Program) in its beneficiaries' daily lives

## O Programa de Volta para Casa na vida cotidiana dos seus beneficiários

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## Abstract

This article presents the methodological course of a multi-territorial and multi-method research, which evaluated the effects of the De Volta para Casa Program (PVC - Back Home Program) in the process of social reintegration of people who had long periods of psychiatric hospitalization. PVC was established by the Law No. 10,708/2003 to fulfill a fundamental role in redirecting mental health care in Brazil and consists of a financial aid that facilitates the process of deinstitutionalization and social reintegration of its beneficiaries. In each municipality, a Research Monitoring Committee (CAP) was implemented, composed of beneficiaries, workers and representatives of the local community. The history of PVC was obtained through documentary analysis and interviews with the main actors responsible for the implementation of the program. Through participant observation and individual and collective interviews, we sought an approach to the daily life of the beneficiaries, aiming at the elaboration of narratives about their life story. Finally, the progresses and challenges in the construction of affective networks and psychosocial support were analyzed. The conclusion is that PVC has effectively promoted important individual gains to the beneficiaries, contributing to their social insertion in the daily life of the cities. Moreover, it proves to be equally important in the path of building citizenship and increasing contractual power in the context of the Brazilian Psychiatric Reform.

**Keywords:** Psychiatric Reform; Mental Health; Deinstitutionalization; Psychosocial Rehabilitation; De Volta para Casa Program (Back Home Program).

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## Resumo

Apresenta-se o percurso metodológico de uma pesquisa multiterritorial e multimétodos que avaliou os efeitos do Programa de Volta para Casa (PVC) no processo de reinserção social de pessoas egressas de longos períodos de internação psiquiátrica. O PVC, instituído pela Lei nº 10.708/2003 para cumprir papel fundamental no redirecionamento da atenção em saúde mental no Brasil, consiste em um auxílio pecuniário que pretende facilitar o processo de desinstitucionalização e reinserção social dos seus beneficiários. Em cada município pesquisado foi implantado um Comitê de Acompanhamento da Pesquisa (CAP), composto por beneficiários, trabalhadores e representantes da comunidade local. Pesquisou-se a história do PVC por meio de análise documental e entrevistas com os principais atores responsáveis pela implantação do programa. Por meio da observação participante e da realização de entrevistas individuais e coletivas, buscou-se uma aproximação ao cotidiano dos beneficiários, visando construir narrativas sobre cada trajetória. Por fim, analisou-se avanços e desafios na construção de redes afetivas e apoio psicossocial. Conclui-se que o PVC promoveu efetivamente ganhos individuais importantes aos beneficiários, contribuindo com a inserção social no cotidiano das cidades, revelando-se como importante dispositivo no caminho de construção de cidadania e de aumento do poder contratual no contexto da Reforma Psiquiátrica brasileira.

**Palavras-chave:** Reforma Psiquiátrica; Saúde Mental; Desinstitucionalização; Reabilitação Psicossocial; Programa de Volta para Casa.

## Introduction

More than 30 years after the beginning of the Brazilian Psychiatric Reform (RPb), special attention still needs to be paid to the large number of people hospitalized for long periods in psychiatric hospitals, people who have experienced chronic psychic suffering and lost important social ties. This reality demands articulation of the Brazilian Mental Health Policy with other sectors of government, seeking the incorporation of social actions to guarantee the integrality of care in freedom.

From the experience of Italy's psychiatric reform, Basaglia (1996) drew attention to the necessity of deinstitutionalization actions for those who have been in asylum for a long time. In addition to de-hospitalization, deinstitutionalization implies changes in society's relations with insanity and the consideration, based on the psychosocial rehabilitation and the search for the guarantee of rights, for the demands of people with psychic suffering in the redesign of life strategies in the city (Amarante, 1996).

"Not restricted to the technical restructuring of services or modern therapies" (Amarante, 2009, p. 1), mental health care began to require the production of unique strategies, aligned with the clinical and social profile of users. In Brazil and in the world, the last decades have produced, in different spaces, innovative intervention strategies based on new practices and knowledge, to the point that this knowledge has been considered part of a new transdisciplinary field: mental health.

In Brazil, Law No. 10,216/2001 (Brasil, 2001), considered the legal framework of RPb, defined a community model of mental health care that intends to overcome the current asylum model, guaranteeing civil rights to people with mental disorders. The norms produced in the following decade reflected the existence of a focus on the regulation of deinstitutionalization, inasmuch as it attempted to provide social transformations, based on clinical practice and life in freedom in the lives of people who had been institutionalized, on the interface between theory and practice (Amarante, 2001).

Studies on RPb (Luzio; L'Abbate, 2006; Pitta, 2011; Tenório, 2002) indicate the progress of

deinstitutionalization in the country, which would have dislocated, in terms of funding, mental health care from large mental asylums to life territory through the Psychosocial Attention Network (Raps), with multiple components, including “deinstitutionalization” and “psychosocial rehabilitation.” The “deinstitutionalization” component is operated through the Therapeutic Residential Service (SRT), the De Volta para Casa Program (PVC - Back Home Program) and the Deinstitutionalization Program; the “psychosocial rehabilitation” component is operated through work strategies, income generation and social insertion.

SRT was the main strategy to respond to the demands for housing from former long-term patients, which are houses located in urban space that shelter up to eight residents (Brasil, 2000). Since its implementation, this service has been the subject of studies that demonstrate its potential for the lives of people who live in them, confirming its important role in the consolidation of RPB (Massa; Moreira, 2019; Ribeiro Neto; Avellar, 2017; Wachs et al., 2010).

PVC, in turn, regulated by Law No. 10,708/2003, is a monetary benefit, a rehabilitation aid “for assistance, follow up and social integration, outside the hospital unit” (Brasil, 2003). This strategy is based on recommendations of the Pan American Health Organization (PAHO) and the World Health Organization (WHO) for the field of mental health, aiming to replace the model of assistance centered in specialized hospitals for one that is executed by community-based territorial services.

The program is the achievement of a historical claim of the Brazilian Psychiatric Reform movement, formulated as a proposal at the time of the Second National Conference on Mental Health in 1992 [...] It is one of the main instruments in the process of psychosocial rehabilitation, according to the world literature in the field of Psychiatric Reform. Its effects on the daily lives of people who leave psychiatric hospitals are immediate, as a significant intervention takes place in the power of social contractility of the beneficiaries, enhancing their emancipation and autonomy. (Brasil, 2005, p. 16)

By favoring the insertion of the individual into the productive and social environment through a specific financial resource, nominal to former patients of long psychiatric hospitalizations, PVC has proved to be an innovative technology of social protection and support to resocialization, which can result in more qualified life processes. However, it was possible to confirm that few investigations were carried out exclusively dedicated to this strategy. In the literature, only seven specific references on PVC were found: two scientific articles, two master theses, a doctoral dissertation and two book chapters. All of them report local experiences, none covers the program at the national level.

Important iconographic material (photos, posters and videos) about De Volta para Casa exists, but in contrast, a very low number of articles on this strategy is identified in literature. (Fiocruz, 2015, p. 36)

Among other studies that also address PVC, we highlight the report of an experience of deconstruction of a psychiatric hospital in the countryside of Northeast (Kinker, 2007). In this report, it is possible to follow the unfolding of an intervention that occurred in 2005, from which different reception, support and housing services were structured for former patients. It is an intense field journal of one of the intervenors, written in the heat of the work, with rich details about the hospital universe and the need for transformation. Robortella (2000) also presented an intervention report from his experience at Casa de Saúde Anchieta, in Santos, SP, describing the users’ lives, stories marked by exclusion and abandonment, which, after the intervention, find a life in freedom.

Studies about life outside the hospital also bring reflections on the moment of transformation from a contained, excluded, intramural life to an expanding life. Moreira (2007b) analyzed several SRT that settled in a municipality in the state of Espírito Santo, emphasizing that the residents were slowly integrating into the city and building a city, a space for themselves, from their place of living. Each person is building their own different way of living in the city regarding the SRT. What stands out, when highlighting this question, is that new existential

territories are being constituted when “insanity” starts to inhabit the city in its various forms. The fact that the community experiences daily situations with these residents enables social exchanges that transform the way the city/insanity relationship is shaped from the possible neighborhood.

In another study on SRT and PVC, in the Central-West region, the authors emphasize the importance that any institutional function of State responsibility that has such an objective “should prevail through the articulation of actors who assume the function of care as intermediation between the beneficiary and the social life, and not as restrictors of their choices, of their ways of being and living” (Lionço et al., 2010, p. 351). This type of aid should be considered not only as assets and resources to be guaranteed, but above all as a political device to recognize the vulnerabilities of these people who have been in neglect for many years in psychiatric hospitals.

Studies on PVC (Campos, 2008; Lima; Brasil, 2014) reveal the effects of the benefit on people’s lives in two cities from different Brazilian regions. The data enable the direct association between the benefit and the possibility of leaving the hospital and exercising citizenship: basic rights, political right - to be a voter - and also the social right to access public policies.

In another study, Lima and Brasil (2014) investigated the contributions of PVC to the deinstitutionalization of SRT residents in Salvador and showed that part of the aid is collectively used to cover SRT maintenance costs, but the other part is directed to the payment of self-care services, such as beauty salon and barber shop, purchase of dental prosthesis and personal objects such as watches, accordions and costume jewelry.

Franco and Stralen (2015) reported the use of public spaces (squares and parks), as an important resource in the process of insertion in the city, and concluded that PVC made the exit from the hospital possible, which allowed access to public policies and circulation in the city, enabling the appropriation of their houses by choosing and acquiring furniture and utensils.

Screen survey emerged, thus, in a subsequent context to the implementation of the program by the Ministry of Health (MS), but still of low production of

investigations on PVC. Motivating questions were: How do beneficiaries of PVC live? What is the psychosocial rehabilitation work performed after the insertion in the program? How does the municipality monitor, value or contribute to the administration of PVC?

Graph 1 shows the historical series of active beneficiaries in the program. Since 2004, the year of its institution, until the end of 2015, the curve of beneficiaries included in the program increased. Initially, growth was higher, while in recent years it has increased, but with a smaller number of new registrations.

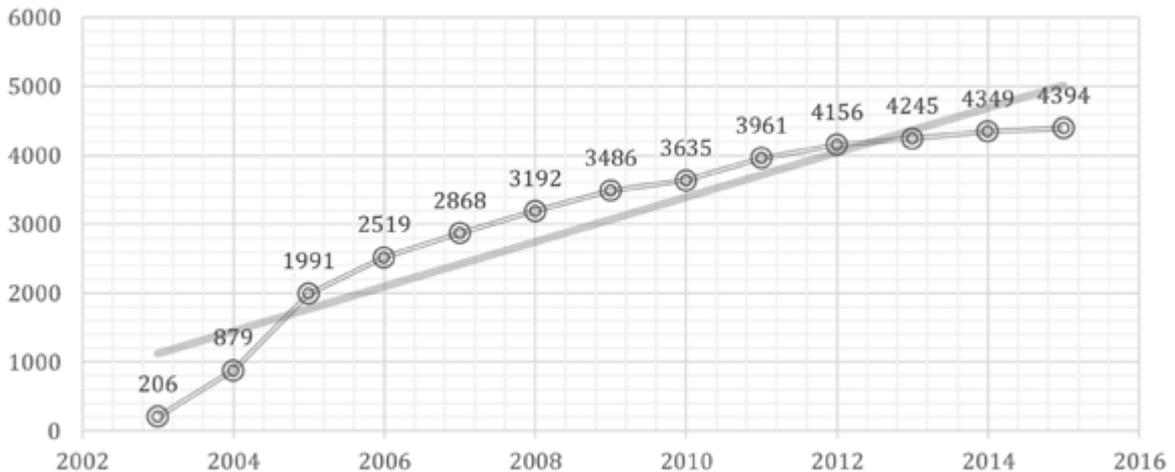
The program has already reached more than 5,000 beneficiaries. However, in December 2015, 4,394 users were included, distributed according to Graph 2.

In absolute numbers, Graph 2 shows the following distribution: Southeast with 2,846 registered users; South with 450; Northeast with 831; North with 36; and Central-West with 231. These data reflect the historical concentration of the psychiatric beds in the Southeast and Northeast regions and the greater implantation of substitute services to mental asylums also in these regions.

Graph 2 also highlights the concentration of beneficiaries in the Southeast region, followed disproportionately by the Northeast region. This concentration in the Southeast is directly related to the high number of psychiatric beds that already existed in the states of São Paulo, Rio de Janeiro and Minas Gerais. Consequently, more processes of deinstitutionalization, including implementation of substitute services, occurred in these states. The other four regions follow this ratio proportionally to their number of residents in psychiatric hospitals. However, some people still need to be deinstitutionalized throughout the national territory.

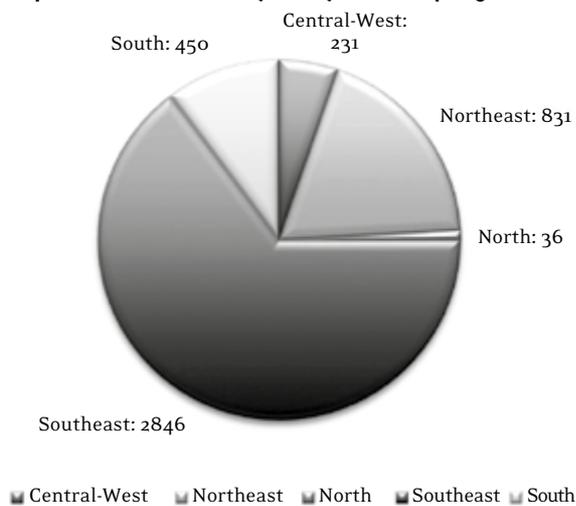
Considering the need to list the dimensions of PVC in the scenario of RBp and the urgency to present data that would allow to visualize the repercussions of this psychosocial rehabilitation device, this study analyzed the PVC inserted in the process of deinstitutionalization. In this sense, this article presents the design and the methodological approach of the evaluation research of PVC in the social reintegration process of people who had long periods of psychiatric hospitalization.

**Graph 1 – Historical series of active beneficiaries in the program**



Source: Ministry of Health (2015)

**Graph 2 – Distribution of beneficiaries by region**



Source: Ministry of Health (2015)

Coordinated by Fiocruz/Brasília, in partnership with researchers from 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, the screen survey aimed to evaluate the role of PVC in the scope of the Brazilian Psychiatric Reform. Researchers from Universidade Federal de Pernambuco (UFPE) and Universidade Federal de Campina Grande (UFCG) also participated.

## Methodological approach

The study had a broad methodological approach to process an equally broad set of information necessary to carry out a comprehensive analysis of PVC as a health policy inserted in the MS processes. Considering that the method must be consistent with the principles that guide the Brazilian National Health System (SUS) and the National Mental Health Policy, we opted for a participatory research model, in order to guarantee the “voice” of the greatest possible number of actors in the investigative process.

The demand of the MS for a national survey led towards a multi-territorial and multimethod research in three dimensions. The first dimension reconstructed the historical-political trajectory of the program and its beneficiaries, from documents, individual interviews and focus groups, as well as personal records of the researchers. The second one pursued an approximation to the daily life of the oldest beneficiaries of PVC in 11 cities that underwent MS intervention in 2004. The third dimension corresponded to the analysis of networks from the database generated in the first two.

The thematic scope of the research demanded the triangulation of methods and researchers from Rio de Janeiro, Distrito Federal, Bahia, São Paulo,

Pernambuco and Paraíba, who participated from the conception of the project to the data collection and analysis. The triangulation of researchers is executed in studies that intend to construct denser analyses, as far as the definition of procedures and categories undergo negotiation processes between actors (Koizumi, 1992).

We designed six possible profiles of research participants, and the same subject can be included in more than one profile. On the other hand, the description of these profiles indicated the expansion of the sample of participants in the search to absorb the maximum of possible perspectives to understand the object of study. Therefore, we considered for this research:

1. Users: people registered in the PVC, or whose registration process is in progress;
2. Formulators: people directly involved in the design, formulation, proposition and institutional implementation of PVC;
3. Managers: people institutionally responsible for PVC in the three spheres of the government, including the category of technical reference established in the PVC, being health professionals who monitor the program in the municipality;
4. Professionals: workers in the Raps of the municipality, involved in the psychosocial rehabilitation of beneficiaries of PVC (including reference professional of the points of attention to which these beneficiaries are attached);
5. Representatives of social movements: people participating in the social movement, in municipal health councils or in the Mental Health Commission (CISM) from the National Health Council (CNS);
6. Representatives of the legislature: people who are members of the National Congress, during the drafting and promulgation of the PVC Law, or members of the Parliamentary Front in Defense of the Psychiatric Reform and the Anti-asylum fight movement.

The research was approved by the Research Ethics Committee of Fiocruz/Brasília, with opinion number 1,699,082, and it was developed between the 2015 and 2018.

## **First dimension**

The first dimension had a longitudinal aspect to allow the formulation of a national mapping of PVC as contemporary public policy (2003-2015). At that time, qualitative and quantitative methods were integrated, using documentary sets designed for the formulation and implementation of the policy (primary documents), semi-structured interviews with the formulators and operators of (federal/municipal) PVC and consolidation of data, which allowed the identification of PVC beneficiaries profile via the information system used at federal level, as well as secondary documents about PVC.

In this dimension, individual and collective interviews were carried out over the years 2016 to 2018 with key formulators and actors in the development of PVC at national level. All the people contacted accepted it and had unique moments to remember their role and participation in the program, as well as its importance for the beneficiaries and the RPb.

The formulators and people directly involved in the conception and proposition of PVC, guided by Basaglia's (1996) reports on the Italian deinstitutionalization process, emphasized the commitment to citizenship and to the implementation of contractual power that life in freedom encourages and requires.

## **Second dimension**

Once the municipalities participating in the research were identified, the Research Monitoring Committee (CAP) was implemented in each territory. CAP has already been used in other evaluation studies, having been called "Scientific Committee" by Onocko-Campos et al. (2008), and applied by Furtado and Nakamura (2014) as a mechanism for the exchange of information from the group of participants, promoting the circulation of opinions, doubts and criticisms about the progress of the research.

Following this first approach to PVC as part of the National Mental Health Policy, the data and beneficiary profiles of the chosen cities were further

developed to recognize their existential territories, correlating them whenever possible to Raps. The complexity of this dimension was great, since research activities in the 11 fields were planned, debated and analyzed from consolidated work in workshops that sought to align the work of different teams and standardize field instruments.

In the second dimension, the longitudinal dimension (first dimension) was followed by a temporal cut with micro-location in the municipal territory of beneficiaries who were linked to PVC between 2004 and 2006, when the first interventions in psychiatric hospitals were carried out under the command of MS. Thus, in this second dimension of the research, the beneficiaries and their insertion in community, organization, institution and their structured ways of life after leaving the hospital were investigated.

In some cities, pairs of researchers were formed to accompany each beneficiary participating in the research. In other cities, the beneficiaries were accompanied only by one researcher, always generating written records in logbooks, which supported the construction of the narratives.

Field journals, as participant observation record tools, were standardized in a semi-structured format to ensure a common agenda for researchers. After the process of observation of the daily life of the beneficiaries, 107 narratives were constructed, one for each beneficiary of the PVC selected for the research. The participant observation method enabled the encounter and direct dialogue with the beneficiaries of the PVC, revealing important aspects about their places of residence, besides indicating the relationships that were constituted from life in freedom.

In this phase of participant observation, we found different inhibitions in the construction of new less hierarchical social contracts stimulated by the circulation in the city, as well as excess caregiving, with repetition of relations or defenses of the beneficiaries coming from the institutionalized life. These findings are similar to those found by Franco and Stralen (2015), who analyzed the daily lives of 20 patients of a psychiatric hospital in the deinstitutionalization process through research activity in the city of Belo Horizonte.

By emphasizing the necessary approximation with the research subjects, the study concludes that this process requires sensitive listening and planning by health professionals, but also the involvement of the beneficiaries, as the hierarchical relationships of hospital power translated into practices of domination reduce the possibility of inaugurating other relations in the territory, besides restricting new experiences of social exchanges.

This concern also emerged in the semi-structured interviews with the municipal managers of PVC, during informal conversations and in CAP and was part of the material that served as the basis for the construction of dense narratives about autonomy and contractual relationships among people.

After understanding this challenge, one can revisit Venturini's (2010) words that describe the process conducted in Imola, in which by providing housing to people after psychiatric hospital discharge they sought to understand the powers and resources in the territory:

We asked ourselves what was the soul of that territory, how to achieve intersectionality between social and health services, but we also asked ourselves what are the needs the community has, its deficiencies and if we could enter the community offering a gift for the citizens (sometimes it was a simple soccer field near the house, a workshop, a joinery, a useful activity not only for the guests of the house but for the community). It was a way to claim rights of citizenship, not as a passive way of meeting the needs of an incomplete citizen, but as an active exercise of a complete citizen, who claims reciprocity. And perhaps it was the inversion of perspective, this look beyond the stereotypes of our present, the most important for the community. (Venturini, 2010, p. 475)

As the main product of this second dimension, narratives that tell the life stories of the beneficiaries were constructed focusing on the possible dialogues of the money-autonomy dyad: after all, "what power does money bring?". Although the "technical reference" responsible for accompanying the beneficiaries of the program in everyday situations, including the administration support of this

financial resource, the learning process and the experience of new contractual relations are considered the core of psychosocial rehabilitation strategies in everyday life. Regarding that, PVC contributes to the permanence of these people in the community environment, ensuring their dignity and human rights, as proposed in the Caracas Declaration (OMS, 1990).

In the course of this dimension, different processes were found: on the one hand, struggle to survive, precarious housing, family ties not yet restored, hard experiences with stigmas and prejudices; on the other, new social insertions, other affective bonds built and creative forms of network support are highlights in the narratives of the beneficiaries of the program.

In all fields, researchers were able to be with the beneficiaries long enough to understand their life routine after the insertion in the program, considering all the transformations occurred by the presence of the financial resource, from the beginning to this day.

### **Third dimension**

To consolidate the possible analyses based on the first two dimensions of the research - referring to the historical trajectory of PVC as public policy and the ethnographic research of the itineraries of the beneficiaries -, a database with information was built (from 2004 to 2016) to generate mappings and later analyses of the networks. The third dimension of the research will need to condense findings of dimensions one and two into the appropriate tools (ORA and Gephi softwares) to build social networks analysis (ARS) in a projective analytical universe.

ARS maps the types and levels of interlacing between subjects and institutions to better understand PVC, the Psychosocial Attention Network and the trajectories of the beneficiaries. This mapping expressed in graphs representing the interactions between the actors and the different territories will present the condensation of variables that will enable the consolidation of multidimensional evaluations of the De Volta para Casa Program. In this sense, the ARS, by presenting the current scenario graphically, provides the

identification of future events - inputs to visualize the critical factors and potential intervention hypothesis - for the composition of possible scenarios for the field of mental health.

From this mapping, the generation of hypotheses for the possible scenarios will subsequently be conducted in a participative way in rounds of conversations called Prospective Dialogues, improving the understanding and validation of the analyses. The projective basis of this methodological approach is anchored in the scenario building method, aiming at consolidating a set of orientations and strategic actions for a future horizon for the specific context/situation of PVC/Raps, which enables the mobilization of the actors for the development of collective intelligence around knowledge that grants practical interventions to qualify policies.

However, once there was a change in the MS management, with budget resizing and considerable cutback in research, a decision was made to interrupt the funding, so the third dimension of this research was postponed without possibility of being conducted at the moment.

### **Final remarks**

Different products were planned at each stage of the research. From the documental analysis we could foresee the necessary update of the Program Manual; construction of an instructive for technical references and workers; guidelines to managers to improve the access to the registration system; periodic execution of information and training seminars; publications; institutional video. Of these products, the 11 cities had guidelines to managers when giving feedback of results, aside from publications and institutional video produced. The other expected products were suspended, as a result of the interruption of the financing.

Findings of the field showed the need to publicize the invisible stories of the beneficiaries, with the publication of their life narratives; presentation of feedback final seminar; publication of articles in journals; reports. The findings also showed the influence of PVC on the lives of people with severe psychic suffering, who need to balance their needs

for autonomy and contractility. Thus, this study was able to show other important aspects of the living conditions of these people and the management process of this public policy.

Triangulation of researchers from different public institutions in three regions of Brazil with theoretical and practical knowledge in the field of mental health enabled the building and development of this research but posed some challenges. The diverse theoretical views, the large number of narratives to be analyzed and the management of the research in a period of many uncertainties and conflicts in society and in governments were some of the challenges faced.

At the same time we live these challenges and uncertain moments, we realize that evaluating a public health program through the lens of those who receive this policy was certainly successful. To listen to people who, for many years, were isolated from their rights was the right choice. To pay attention to those who suffer from public policy may be the great solution to the “bottlenecks” found, including in the screen research.

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### Authors' contribution

All authors contributed equally to the preparation and final revision of the text and graphs.

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# 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