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Spaces for differences: dwelling after deinstitutionalization

Ana Paula Baltazar and Silke Kapp
School of Architecture, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil
Augustin de Tugny
School of Arts, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil, and
Juarez Pereira Furtado
Department of Health, Education and Society, Universidade Federal de São Paulo, Santos, Brazil

Abstract

Purpose – The purpose of this paper is to report on the point of view of architecture of an interdisciplinary research on housing and social integration of people with severe mental disorder (SMD) in Brazil after deinstitutionalization. It first aims to present the need for a qualitative evaluation of the way people with SMD deal with their living spaces (house and city); then to describe the method adopted to approach people living under control – in therapeutic residential services (SRTs) proposed by the State as the only alternative model for those leaving psychiatric institutions – and people living alone – with little psychiatric assistance and no dwelling support provided by the State. It aims to conclude with a discussion of the observed dwellings pointing towards the need to accommodate differences in any housing model adopted by the State.

Design/methodology/approach – The qualitative evaluation enabled the focus of participant observation on the way people interact with each other and with their living space. The authors followed the routines of chosen people with SMD in three different cities in Brazil and provided reports for the whole group to analyze them.

Findings – It was found that those living in SRTs are much more obstructed by institutional control than those living alone. Despite the difficulties and fragilities of those living alone because of the lack of support, they end with more possibilities for autonomy and social integration.

Originality/value – Most research on the subject approaches objective housing issues focusing on statistical results. This research evaluates qualitative dwelling issues, summarizing little pointers for future health policy on housing for people with SMD.

Keywords Brazil, Social policy, Mental health services, Community care, Institutional care, Psychiatric deinstitutionalization, Social integration, Housing, Halfway house, Supported housing

Paper type Research paper

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Psychiatric deinstitutionalization in Brazil

The so-called psychiatric deinstitutionalization means that people with severe mental disorder (SMD)[1] no longer live in psychiatric hospitals and are supposed to be socially (re)integrated. For that they need appropriate dwelling and support. In the Belgian City of Geel, this demand was met for centuries by the halfway house – the billeting of people with SMD in family homes (Clark, 1967; Rog and Raush, 1975). In Brazil the experience of the halfway house resonates since the beginning of the twentieth century in the proposals of the two psychiatrists; Juliano Moreira and Franco da Rocha (Moreira, 1906; Urquiza, 1991; Oda, 2005). Both advocated housing people with SMD in family homes. However, this was only meant to complement the function of the psychiatric hospital by providing a mediated form of reality – a soft landing after discharge. It took another century before the centralised model for mental health assistance in Brazil was systematically replaced by a community care model. In the late 1990s, pilot projects were undertaken in the cities of Porto Alegre (Neto and Oliveira, 2003), Ribeirão Preto (Guimarães and Saeki, 2002) and Campinas (Braga-Campos and Guarido, 2006; Furtado and Pacheco, 1998), all of which attempted to address the issue of isolation. Typically, people with SMD – in particular those discharged from psychiatric hospitals – have very fragile family bonds and severely diminished social function. In 2000, based on these pilot projects, the National Health Ministry finally established the Residential Therapeutic Service (SRT) as part of the National Health System[2].

Like halfway houses, SRT units are based on the family house model. Each unit accommodates up to eight patients who are permanently assisted by a carer[3] and provided with clinical and psychosocial support on an outpatient basis from the municipal health service. An internment in a psychiatric hospital for two or more uninterrupted years is the sole criterion for access to a SRT. Although the number of SRTs grew from 500 in 2008 (with 3,000 dwellers) to 608 in 2012 (with 4,080 dwellers; Brasil, 2012), it is still not enough to shelter every discharged patient, which means that many need to find their own way when they leave psychiatric care, be it alone, with family, on the streets, or in any other way.

Apart from SRTs, Psychosocial Attention Centres (CAPS) provide day-care, psychiatric support and opportunities to socialise for people with SMD. They might report to their local CAPS on a daily basis or whenever they want, freely coming and going. The number of such centres, which usually operate out of rented houses, is also growing – 1,326 centres supporting 397,800 users in 2008, and 1,850 centres supporting 555,000 users in 2012 (Brasil, 2012). For the 30 per cent of CAPS users who have no access to a SRT (Kantorski, 2008), this is the only option for public psychosocial support. Besides the SRT system, there is no public policy in Brazil to house people with SMD. However, as widely reported by different researchers, housing is an important social determinant for general health (Thomson *et al.*, 2009) and particularly for the integration of people with SMD (Beaulieu e Dorvil, 2004). Housing, labour and social network constitute the fundamental triad in the process of their rehabilitation and social integration (Saraceno, 1999; Dorvil, 2004).

Method

Qualitative evaluation has been used as a research method extensively since the mid 1980s to evaluate health programs and services (Bosi and Mercado, 1990; Furtado, 2001). It has also been used to evaluate different modes of dwelling for future developments and decision making (Hartz, 1997; Worthen *et al.*, 2004). It takes into account the participation and perception of all people involved in an action or situation, focusing on relations and representations as sources of success or constraint.

The qualitative evaluation on which this paper is based was to investigate the modes of dwelling of people with SMD living in SRTs and by themselves with support from a CAPS. Our main concern was to understand their *habitus* and how it contributes or constrains their social (re)integration. We understand *habitus* with Bourdieu (1990, p. 53) as:

> [. . .] principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them.

In other words, the evaluation focused on the "unaffected" daily interactions between people and their environment (the house and the city). As Golembiewski points out (in this issue), most of these interactions are around affordances: "opportunities to engage and to act in well-learned or instinctive ways" (p. xx). Affordances are seen here for their capacity to excite or inhibit behaviour, gestures, and social interactions, as well as their role in the formation of identities, integrating collective and individual memories.

To evaluate the role of *habitus* in social (re)integration of people with SMD, we used the ethnographic participant observation method (Kluckhohn, 1940), looking at dwelling beyond the physical or functional use of space. In each of three Brazilian cities (Belo Horizonte, Santo André and Goiânia), a team of researchers was put together. These included senior researchers, graduates and undergraduate students of Anthropology, Architecture, Psychoanalysis and Public Health. Each local team was responsible to report to the whole group on its observations of two SRTs and of two people with SMD living outside the SRT system. In each SRT at least two people were closely observed. The observation took place over a period of a year, with alternate weekly visits to the SRTs and the subjects who lived elsewhere.

In the six months prior to the field research a script was prepared with issues concerning each discipline involved and instructions on how to organise information. The script was tested and adjusted at the commencement of the field work. Personal information, psychological health status and details of how subjects where diagnosed were recorded. The script also required sketches of the dwellings and to look closely at objects, spaces and events in the house and the urban environment as affordances that would help to reveal people's *habitus*. Each local team sent one to three researchers for each visit (usually two researchers), who provided individual reports of the observations for the whole group. The reports were written in detail so others could interpret them in their own ways (Sacks, 1985). All the reports were finally put together and analysed from the perspective of each discipline involved. This paper provides the perspective of architecture. We have analysed all the reports concerning all six SRTs, and all the subjects, but we provide here just a small sample of the cases to allow the reader a feeling for our interpretations. Although the interpretation was not intended to generalise conclusions, we found interesting material with universal relevance.

The SRT: living under control

All the SRTs in our sample are installed in family houses rented by the State from private owners, and usually located in poor suburbs. In most cases, they are old and badly maintained, so that the marks of previous uses are still clear. Although each is configured differently, the division and articulation of spaces remain typical of a family home. The carers (usually four for each house) work in shifts and do not live there, though all of them reinforce the family home character, as if it were possible for their dwellers to "feel at home" there. In Santo André and Goiânia the sample SRTs were unisex, while in Belo Horizonte they were mixed.

Superficially, the family house model appeared to be a close approximation of the halfway house and previous models for social (re)integration. However, it became clear very quickly that the model was not emancipatory. Given that the dwellers of a SRT neither have nor claim to establish family relationships, a space that pretends to be a family house leads to ambiguous situations. On the one hand, the family house spaces suggest wide possibilities of establishing identity, expression and development. On the other, the family house is used as instrument of control, imposing on both dwellers and carers specific roles to fulfil.

In most cases, the change of use (from private homes to SRT) meant only small functional interventions, such as a secondary entrance becoming the main entrance, or a living room becoming a bedroom. Furniture and other objects of utility give the impression of a conventional domestic environment. Yet rooms and objects of a SRT are treated as (public) "assets" and have their uses or places defined primarily by the needs of the transitory carers (supervision, control, ease of cleaning, etc.). Under no circumstances were they elements with which the dwellers configure their own spaces and enhance their own possibilities for action. Even privacy, which is one of the main features of a "home", is completely neglected, so that most inhabitants have locks in their closets and dressers, and they often manifest discontent and distrust of the carers.

Following the same pattern, the places for collective living – mainly outside areas, kitchen and eating-room – are provided with elements that should trigger social integration and the free use, but their actual use is inevitably organised by the carers. One of the houses for instance, has a pleasant external area with barbecue. The well-meaning carer told us that the dwellers love barbecues, so he often uses it to cook lunch. Nevertheless, the "barbecue" is not sociable at all, because dwellers are not permitted out to the barbecue area while the meat is being prepared. The area turns out to be a kitchen for the use of the carer alone.

Although SRTs do not confine people creating a boundary between inside and out, like the "total institutions" observed by Goffman (1961), the routine established in SRTs organises time and space according to meticulously programmed activities; there is a schedule for everything. Residents have specific times to eat, take medicine (in the morning, afternoon and evening), to go out near the house, to have a shower, to stand at the front door, to socialise, and to "work". Many people undertake different jobs, but to observers it is an inescapable fact that they have little function other than to keep hands and mind occupied: "Idle hands are the devil's tools", one person with SMD told us. Such activities are not helping social integration. If the organisation of time in big asylums aims not only to discipline but to inhibit people's development as Goffman states, the SRT is no different: discipline and constrained development are inevitable consequences of such total organisation of time and space.

Goffman (1961) claims the confined individual is subjected to a personality created for him or her by the carers, by society and by him or herself. Even if not technically confined, this also applies to SRT residents. There is no (or very little) escape for the dwellers to free themselves from an identity created for them. For instance, a woman in one of the unisex SRTs assumes the role of a housekeeper and proudly makes coffee and cake for the afternoon tea. Even if this might be a healing activity for her (Golembiewski, 2012), the carers take advantage of such assumed roles. They do not really entrust her with the responsibility for keeping the house, but use her engagement to control her cohabitants, because making coffee and cake defines a fixed afternoon "socialising" time. Another example is a resident who has his social (re)integration obstructed by the constant reassertion of his incapacity and lack of autonomy. In one of his weekly trips to the cinema, he took a taxi. He got slowly out of the house and, keeping his rhythm, got into the car. When seated, he initiated a movement with his arm towards the seatbelt, which was done so slowly that it immediately struck both the carer and the driver, each expressing their frustration with the resident's tempo, which in itself caused no harm whatsoever. The confusion created was such that the resident got flustered and irritated, reinforcing the others' previous image of him as socially inept and physically incapable.

The relative mobility of SRT residents within the city – they go to local shops, community centre, cinema, go dancing, take taxis and busses – is only ever to pass the time. Their activities are not integrated into greater society in any way, be it socially (as expected for a SRT) or at least functionally (as expected in a capitalist context; Gorz, 1988). Distorting Saraceno's ideal triad of dwelling, labour and social network (1999), the SRT becomes a caricature of the family house, the occupational therapy becomes a caricature of work and the social network is essentially restricted to people within the (new) small institution. The promise of social integration of SRT residents did not occur in any of the sample cases the team observed.

The hierarchical relationship between carers and people with SMD is typical of the total institutions described by Goffman (1961). That is, basic needs are collectively met and bureaucratically managed. If this hinders the freedom of dwellers and affects their social integration negatively, one cannot disregard the difficult position of the carers, who are required to do all the housework and provide clinical support without training or sufficient pay. Routines facilitate their job and help to keep the SRT in order. Unfortunately, the "homely" SRT model of care does little to undermine the total institution and prevent life under control.

Living alone and the CAPS

Whether they live alone or with support of a relative or acquaintance, people with SMD who live outside of SRTs seem to be in a more fragile situation than those living in SRTs. However, after analysing their fragilities and the way they socially interact, the opposite becomes apparent. They have more affordances for social integration – even taking into account the negatives: the patients' fears and frustrations. This section reports on our observations of people with SMD living alone in diverse situations. Here, we draw on a few examples to illustrate both the fragility of people living alone and their relation to the city.

Everyone who we observed with SMD who lived alone is much more exposed to the harshness of life, and thus to suffering, than those living in SRTs. For instance, a man with a long history of internment who now lives alone in a little room in a tenement in a city centre, wrote a strong criticism of the mental health system, both as graffiti on the wall of the CAPS he attends and in its newsletter: "The anti-asylum struggle ends with eternal punishment" and "The State attacks the body of man." He is very critical of his situation following psychiatric deinstitutionalization, saying: "with the end of asylums run by the State, new private asylums will be opened and needy people will no longer have access to treatment." This man oscillates between finding it extremely difficult to live in society and envisaging a possible life beyond confinement. It is the lack of support that makes his everyday life so tenuous. He needs to do everything, all by himself. Even when he most needs psychiatric support, he must be responsible and strong enough to attend the CAPS. There is no close monitoring of those living alone.

People with SMD living alone find various ways to cope with life and their fears. For instance, one subject lives in a little house behind his sister's, but never feels he belongs there, yet he is not able to develop on any ideas of leaving. The little house is under construction and he restricts himself to the use one bedroom and the bathroom, which he must keep absolutely clean; but it's difficult because the other rooms are deposits of building materials that his brother-in-law intends to use to complete the renovation. Even though he lives alone, he is tutored by his sister, who provides food and medicine, receives and manages his retirement money, and continually reminds him that she is doing him a big favour. Because he does not dare to interfere with the areas under construction and has to keep out of his sister's way lest he be lectured on the imbalance of their relationship, he escapes by keeping to himself in his room with his door closed. The environment has a strong smell of mildew and sweat, it is dark and closed, and he stays there, lying down, listening to music most of the time. If ever he goes out, his dependency of his relatives is reinforced. He yearns for a world of sociability, but when he greets people and they reply "fine, thanks", he take such answer literally, and it makes him feel like the only person in the world with problems. As he lives in an outskirt of town, his immediate neighbourhood is quite restricted, so his favourite place is the city centre, where he goes by bus. He says he loves to walk around to see the shop windows and fantasises that he would love to live there, but at the same time the coldness of people in the city really bothers him. He likes the sociability of the CAPS, mainly because of the communal lunch, and he has already thought of moving to a SRT. Nevertheless, when he talks about this to his relatives they aggressively discourage him, perhaps because they need his retirement money. Ultimately he is unable to make up his mind and leave. This man clearly needs stability and depends hugely on other peoples' approval, which makes it a paradox that he lives on his own. Despite all his psychological fragility, he manages his life with much more independence than anyone living in an SRT.

An almost opposite case is that of a man who lives in a boarding house with other 17 people with SMD also living on their own. This man clearly prefers collective and public spaces to domestic and private ones. His itinerancy is most cherished than any living space. He moves everyday between the boarding house, which he rejects, and the CAPS, which is his preferred living place. Even if not required for a daily treatment, he goes to the CAPS every day and is appreciated by the workers and other patients for being helpful in small services. Every weekend he visits his ex-wife's house, where he spends the day but never sleeps over as he does not feel comfortable and is constantly annoyed by jokes concerning his slowness. In contrast, the main advantage he sees in the boarding house is that no one ever pays attention to him; no one asks him anything, he might come and go as he wishes. He actually seems to find comfort in his anonymity and in the instability of his itinerancy. He demonstrates great sensibility for public spaces such as a forgotten little alley in the city centre or the interior of a church he appreciates. This man is quite capable of living alone, despite his discontentment with the boarding house. Clearly he manages to exchange social experiences in public spaces but finds it difficult to deal with private spaces. This makes us question whether a more friendly housing model would suit such a demand for exchanging socio-spatial experiences.

A strong desire for city life is also part of the memory (or delusions) of a 65 year old woman, who lives alone in a little house rented by a CAPS, behind the house of an SRT carer. She told us that she lived in a small city before her son sent her to the asylum. Since deinstitutionalization she has already lived in two SRTs, and now lives on her own, proudly saying that "there is nothing better than our own house". Her narrative is always permeated by famous people and a range of different places and cities, which she had supposedly known before her internment. She believes owning a house in a nearby suburb, which she would have built in the past and where she would host the rich and famous – even presidents. This house is her ideal place and she seems to have it as an imaginary safe destiny, after her interval living in the current place. Her narrative of an imaginary geography seems to provide what's so clearly missing from her current situation – a socio-spatial relationship. She often mentions her fantasies of freedom and her wanderlust. But this is in stark contrast to her daily life. She seldom goes out of her house and when she does, she requires a carer from the local CAPS to accompany her. Moreover, she does not feel that any of the places nearby are worth noticing compared to the places that live large in her memory (or imagination). As the SRT residents we studied, she also distrusts the carer, and believes she is being robbed and her privacy is being violated all the time. The difference between herself and the SRT residents is that she does have some autonomy, which enables her to face the carer. However, her life is in a state of permanent suspension: in her imagination, the past and the future are resolved with effortless socio-spatial integration, but her everyday present demonstrates just the opposite. Thus, she seems trapped in the mismatch between her delusional gregariousness and socio-spatial mobility and the reality of her paralysing loneliness.

Another woman of about 45 years of age also appears to be trapped in her present situation, though in a completely different way. She says that as she is "'maniac–compulsive" (*sic*), she repeats herself a lot but cannot bare any other repetition at all: as such she tries to avoid a daily routine. She has no job, no fixed address, and her main daily task is to find a place to sleep. She says:

> I can't always sleep as I have no place to go. I've slept in the streets, in hospitals, beneath the bridge, in corners of slums, in dirty water and mud.

She also sleeps in a couple of friends' houses and keeps her belongings in bags. She seems to recognise her bags, where she keeps her only possessions (mainly clothes), as a sort of private space, but they are also places of conflict. She claims her bags are always out of order: sometimes lost or left in someone else's house, other times thrown out in the streets, where the rain wets everything making her to lose her "good" clothes. What seems to be behind the conflict with the bags is the loss of reference of her private life, which she refuses to attribute to space and time. She believes the opposite: that she is well socially integrated. Besides being always well dressed and wearing make-up, she faces a daily challenge to manage to keep herself "organised". When she feels overwhelmed, she finds refuge in a sporadic visit to a CAPS. She does use the resources there to rest, have a shower, eat, be medicated and "organise" herself until she can go back to her daily challenges, but she never engages in the CAPS' collective activities. She also avoids any sort of economic exchange, refusing to work for money or for anything she needs:

> I do things when I want. For instance, when I see that my friend's place is dirty, I offer to clean it. I offer it from my heart. And if I need, I'll sleep over, but I'll never clean a place in exchange for a place to sleep. I don't want to! I don't want to do one thing to get another.

In their relationships with institutions, including money and commerce, there is always an element of friction that reveals the desires and frustrations of people with SMD living on their own. The positions regarding institutions is always related to their personal process of integration and autonomy in some way. This is in contrast to SRT residents, for whom attempts at autonomy are undermined by hierarchical relationships between carers and residents and by the traditional part of the family house. Together, these inevitably subject residents to subordinate and fictitious roles. Those who live outside the SRTs must negotiate institutions continually – but ultimately on their own terms. Thus, their socio-spatial integration is not obstructed from the beginning, even if it is inevitably difficult and tortured.

To generalise from the diverse situations that we studied, it appears that despite difficulties, distress, loneliness, insecurity, fear and fragility, there are opportunities to construct a sense of identity in the social and spatial context. Despite the disinterest of the urban environment there are socio-spatial advantages in it, even as it exists only in an imaginary geography. There appear to be important identification and emotional affordances in the potential of the "city", whether it is realised or only imagined.

Spaces for differences

In both cases, living under control in SRTs or living alone, the social (re)integration of people with SMD is necessarily connected with their subjective perception and acceptance of the modern metropolis. With this background, those living in SRTs are much more obstructed by institutional control than those living alone. The result is a dilemma:

> The deepest problems of modern [metropolitan] life flow from the attempt of the individual to maintain the independence and individuality of his existence against the sovereign powers of society, against the weight of the historical heritage and the external culture and technique of life (Simmel, 1997, p. 69).

Because of their vulnerability, these "problems" are ever more evident for people with SMD. Those living in SRTs are overwhelmed by controlled circumstances, which mediate their interactions with modern society and with its spaces (the city) and restrict their possibilities of identity and autonomy from the start, while those living alone confront Simmel's dilemma directly, with all the suffering imposed by the experience of the metropolis.

After analysing a range of reports on participant observations, a few of them summarised above, we wonder if there is any possible housing model that would be better able to preserve the freedom to engage in important emotional and identification affordances. The answers are difficult, but we have arrived at a question to contribute to the debate. People with SMD who live alone somehow do manage to engage and to create their own identities alongside their relationships with the city. Perhaps if these people had more support they would not be quite so vulnerable – and perhaps they may then be able to surpass most of their fears and truly become socially integrated. Apart from the daily support of CAPS, which will not interfere with living arrangements, there could be a wider range of alternative models for supported living in Brazil. Living in a parody of a family home, with all the traps of total institutionalisation, persons with SMD will find it very difficult to reinvent themselves. Yet even the SRT model is open enough to be improved, and municipalities might change its regulations implementing new alternatives. In Brazil the amount of people with SMD is surely enough to justify a much greater and more adequate investment on their living spaces than is currently available.

Notes

1. As this terminology has been subject to dispute in Brazil, we decided to adopt the term SMD, translating it literally, instead of using the term "serious mental illness," which is used in the English literature. In our study, SMDs are defined as disorders with more than two years history, and which cause various disabilities including social dysfunction. This definition includes people who suffer mainly from psychotic illness, categorised by the International Classification of Diseases (ICD-10) under codes F20 to F22, F24, F25, F28 to F31, F32.3 and F33.3 (schizophrenia, induced delusional disorders, schizoaffective disorders, nonorganic psychotic disorders, manic episodes and bipolar disorder, as well as major depressive episodes and disorders with psychotic symptoms.) (Rodriguez and Bravo, 2003).
2. The Portaria 106/2000 (Brasil, 2002) defines the basic structure, operation and funding of the SRT system. Funding to support people with SMD comes from the resources that were formerly used to maintain psychiatric hospitals. It must be noted that the pilot projects were much more successful than the SRT system in terms of social reintegration. In Ribeirão Preto, for instance, people with SMD lived in ordinary housing provided by the municipality, focusing on social reintegration more than on protection (of patients and society).
3. The carer in this model is a worker that alternates his or her shift with other workers, and is not a resident. In the first experiments of housing for people with SMD after deinstitutionalization, there were no 24 hour carers, and people were monitored on a daily basis by experienced health and psycho-social professionals. When SRT became officially part of the National Health System, each municipality was free to implement its own regulations. Most municipalities chose a 24 hour a day model. The carers in SRTs are not required to have specific training because their work is normatively considered to be similar to domestic housekeeping. Their renumeration is not compatible with that of health professionals, but with domestic service.

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About the authors

Ana Paula Baltazar is a Brazilian qualified Architect, MArch, and PhD in Architecture and Virtual Environments at the Bartlett School of Architecture, UCL (UK). She is a Senior Lecturer teaching at both graduate and undergraduate programs at the School of Architecture at Universidade Federal de Minas Gerais, Brazil (UFMG), where she also co-leads the research group MOM (Morar de Outras Maneiras/Living in Other Ways). Her current research focuses on architecture as interface, the autonomy of users in the production of everyday space and the simultaneity of design, building and use. Ana Paula Baltazar is the corresponding author and can be contacted at: baltazar.ana@gmail.com

Silke Kapp is a Brazilian qualified Architect, MPhil and PhD in Philosophy at the Universidade Federal de Minas Gerais, Brazil (UFMG). She is a Senior Lecturer teaching at both graduate and undergraduate programs at the School of Architecture at UFMG, where she also leads the research group MOM (Morar de Outras Maneiras/Living in Other Ways). Her current research focuses on critical theory of the production of everyday space and experimental practices for this production (self-management, self-design, open systems, mutability, interfaces).

Augustin de Tugny is a French qualified Interior Architect by Ecole Camondo, Paris, Master in Architecture and Urbanism and PhD in Arts by the Universidade Federal de Minas Gerais, Brazil (UFMG). He is a Senior Lecturer at the School of Arts at UFMG, where he teaches at the Fashion Design course and heads the Department of Drawing. He also collaborates with the research group MOM (Morar de Outras Maneiras/Living in Other Ways), having as his current interest the relation between body and clothes.

Juarez Pereira Furtado is a Physiotherapist, PhD in Collective Health by Universidade de Campinas, Brazil, and University of Montreal, Canada, and post-doctor in evaluation of mental health programs and services. He is a Senior Lecturer in Collective Health at the Universidade Federal de São Paulo (Unifesp) and founder of the Laboratory of Evaluation of Health Programs and Services at Unifesp. He is currently interested in the reflection and practice of health evaluation. He coordinated the interdisciplinary research on housing and mental health that originated this paper.