The right to care: Entering outside in the southern European crisis of welfare

Marta Pérez and Francesco Salvini Ramas

Introduction

In these notes, we share the questions and challenges around care and health that emerged in the research project *Entrar Afuera* (*Entering Outside*, 2016-2018), a multi-site and multi-format dialogue around critical practices of healing and caring in three sites in southern Europe, Trieste (Italy), Madrid (Spain) and Thessaloniki (Greece). As we will see, we focus this text in Trieste and the dialogue with Madrid[*]. Driving us in this project was our common aspiration to reflect about the urban practices of care during and after the crisis that began in September of 2008. However, there was also a common ethic of emancipation in the institutional critique – the examination of how institutions were caring for people in that critical moment and toward a horizon of change – the imagination of how people could use and fashion institutions in order to care for each other.

We started from an intuition that the critique of the economic crisis, and the widely expressed need to defend public welfare institutions being attacked by policies of austerity, could open up questions about the theory and practice of public welfare institutions and their relationship with health, care, and emancipation. In this direction, this article brings together a number of terms and concepts that emerged in our dialogues and encounters and that we consider important in the work of resignifying the right to health as a common practice of

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[*] This project involved an assembly of collectives, institutions, and individuals, in diverse ways. The reader can find more information at www.entrarafuera.net. For Thessaloniki, the contacts have been mainly based on activist practices for universal healthcare when access is denied to particular population groups (migrants with precarious status, long-term unemployed people, etc.).

caring with. Caring with as a constant engagement with the infrastructure of care, and a practice of permanent repair of the welfare state. This repair of infrastructure should not be understood as an exercise of reform, that constantly reproduces and conserves the institution, but rather one that puts it in relation with, and within, the current crisis, as a transformative endeavour and sustainable alternative.

In this context, the crisis emerged as an immanent tool used by government to recompose social production and control. The crisis has been particularly ambivalent in the south of Europe, not only (and dramatically) as the pretext for the mobilization of hate and fear, but also as the frail – but decisive – beginning of new modes of organising care, rights and social change. To put it another way, this crisis carries within it a transformative power: first, because it reaffirms the antagonism between society as a fabric of interdependent singularities and the state. Second, because it is the space in which these interconnections among singularities can institute new modes of collective response to social needs and desires, while destituting and reinventing the state in the meantime.

Destituting, as a practice that challenges and dismantles the instituted, and inventing the state means enacting a reparative capacity that intervenes and changes the functioning of public infrastructures (Berlant, 2016). Looking at the crafting of institutional practice through the lens of 'infrastructural repairing' show us how much institutional invention is a molecular process immersed in social (and contrasting) dynamics. This text aims to contribute to thinking about emancipatory transformations of the state, most concretely in the relationship between policies and social life. If welfare institutions are spaces of control and discipline as much as they are of care, and if neoliberal theories and practices construct an individualist approach to the provision of welfare services, what space is left for social practices to agitate public policies of care? What sustainable practices can we invent to care not only for the self, but for each other while emancipating our society from the imposed constraints of institutional norms?

In dealing with these questions, we share here the dialogue with Trieste, the site with which we have had the strongest engagement with, participating in regular discussions with the healthcare workers and activists based there. In a slow but penetrating manner, these reflections are taking root as part of the discussions on community health and institutions in some of the spaces we are engaging with in Madrid.

In these discussions with Trieste, we have used three concepts to reflect on practices of health and care: Threshold, Contradictions, Translation. As a research group and community that extend beyond the authors of this article, our

research tools have been two-fold. First, drawing on the rich tradition of militant research, we have engaged with practices of health and care in Trieste; and with political and institutional practices for access to healthcare and the right to health and community health in Madrid. Second, we have experimented with the narrative form, seeking to find ways to displace ourselves as researchers in order to develop a shared language with those we were encountering, through the registers and canons of aesthetics and community engagement.

The sites of research

The text we present here moves from field notes from the first research site, Trieste where the dismantling of the psychiatric hospital in the 1970s started a profound experimentation with health and care beyond the limits of mental care and in the urban space. Since the early 2000s, the logic of care affirmed by the Basaglian movement has become a governing force of the social healthcare system of Trieste and the Friuli Venezia Giulia region generally. Trieste can be addressed as a *singular* governmentality that has been experimenting practically with a different logic and functioning of the state-machine in healthcare over the last decades (Salvini, 2016a).

In what sense a singular governmentality? As we will see below, care practices in Trieste are inserted in an institutionalized public system invented in the specific experience of the Basaglian movement, one that put technical knowledge and power at the service of the people within their social environment; this brings a specific mode of conducting and governing ourselves and others, whether professionals or users of the system.

As we have reflected together about the practice in Trieste, some questions emerged for our group in Madrid. These included a consideration of the Madrid's impulse for community healthcare in the 1980s that is now being revisited; the defence of the public system against the policies of austerity and privatization; and how this contributes (or not) to opening up discussions about social and democratic approaches to care and healthcare. These questions are particularly significant in the institutional challenges that Madrid, Barcelona, and many other Spanish cities are experiencing after the social mobilizations of 2011. In this context, with cities governed by parties formed in the wake of these movements, it is critical to elaborate the differences between an experimentation enacted as 'governance' and 'better management', and one enacted through the 'institution of another practice'.

Threshold

In one of her chronicles, Irene R. Newey, one of the research group members, activist and nurse based in Madrid, recounts her first encounter with the Microarea Programme in Ponziana, Trieste. The Microarea programme is a set of interventions into several vulnerable urban spaces in which healthcare programmes, social services, and housing provision intersect. Several local social networks are involved in designing public policies of care at the local level. Because of its social dimension, the Microarea is also the frontier where the logic of the welfare state and its relationship to the logic of medical knowledge becomes more unstable, since the protocols of provision have to be changed according to the situation. The Microarea is also a place, in the neighbourhood, open five or six days per week, where people can just show up to ask for support (on everyday life activities, such as shopping or medication), participate in the activities (for example of socialization) or actively collaborate in the social dynamics of the centre (for example organising the local food bank).

The concept of the threshold emerged as a way for us to think about this site (Stravides, 2015). Inhabiting the threshold between society and the state, rather than affirming the boundaries of professional competence, permits the constituting of another process of care. This threshold is the place where Microarea workers situate themselves, and a condition of possibility, for doing the job they do. As we came to understand through a series of workshops in 2016:

> [in the Microarea Programme] the role of the public worker is not prescribed through a series of limits and duties through which the citizen is included – as part of the state, as the objective recipient of resources, attentions, benefits. [...] In other words, the production of provision happens on this threshold, as a device that destitutes and institutes [the institutional] practice. (Salvini, 2016b, n.p.)

Destituting is the action of disarticulating the crystallized modes of administration, while the practice of instituting configures new operational modes both in the Microarea and in the whole system:

> We are not a service that is in charge of concrete tasks or functions. Therefore, we do not solve each and every problem on our own. The Microarea is a device with an open mandate to activate existing resources, invent new resources, and knit and sustain communitarian bonds. The resources that the program activates can be institutional, such as healthcare services, social or educative support, or tasks related to benefits or to housing; they can also be resources that already exist in the community, that come from the people inhabiting the territory and nurturing their neighbours. (Ghiretti, notes by Newey, 2019)

In Newey's words:

> I feel vertigo, all of a sudden and strongly. Nobody seems to control what is happening: things happen, people come and go, they make and unmake, and I cannot understand their roles. Who is a professional; who is a volunteer? ... I feel overwhelmed by the idea of having to deal with problems as they come up, with the people as they step in. (Newey, 2019)

The experience of losing control (Petrescu, 2005), as expressed by Irene R. Newey, becomes the site in which one must deal with the complexity of the practice of care in the urban context. Losing control means recognising the rights of the user as the starting point of any care practice. It is from this recognition that the reorganization of the institutional structure can and must begin. The institution is no longer a rigid frame that constrains the patients' lives within the limits of the hospital. Instead, the institution is invented by facing its contradictions and reformulating its rules, protocols, and procedures in order to reinstitute itself around the lives of the users.

Contradiction

Losing control is not about renouncing your competencies; rather, it is about taking responsibility around a complex situation. Responsibility appears here as a composed word: the ability to respond to the situation and from within it, where caring consists of a practice that deals with contradictory elements and tries to make sense 'with' the realities around it, rather than 'of' them (Lorey, 2019; Haraway, 2016).

In Trieste, the open-door mental health system has a long and sustained history that comes from the closure of the psychiatric hospital. The risk involved in closing the hospital was that people in distress would be abandoned to their families and/or to poverty, without any social fabric to sustain them. In Trieste, the result was different because the process was different: it attempted to end the sectioning of both the person in distress and the professional in charge of caring but to keep the right to asylum as a personal right to shelter and refuge in the moment of vulnerability.

This involved disarticulating psychiatry as a technology of power (Castel, 1988), breaking not only the established stigma that linked suffering with dangerousness, but also the combination of interests constituted through medical knowledge and corporate governance in the institution of the asylum. At the same time, in order to destitute the asylum, the challenge was to build strong networks within urban life, bringing the technical knowledge and the responsibility of professionals outside the asylum in order to configure new modes of social organization of care in the complex life of the city and sustain the

right to the constitutively difficult freedom of the most vulnerable citizens in urban life (Giannichedda, 2005).

At the same time, it was about destituting and emancipating the position of technicians, whiting the system: the holders of a *techne*, a capacity/mode of doing – against and beyond their traditional role as guardians. Where the technicians at the same time hold power, reinforce violence and feel incapable of doing otherwise. Far from causing inaction or cynicism, awareness of this contradiction invokes the transformation of the institutional practice, as long as the technicians recognize themselves as having a political agency.

In the words of Giovanna del Giudice,

> if the asylum was chains, sectioning, distance, exclusion, segregation, then it was unacceptable to me, and worth fighting against. I don't know if I actually wanted to destroy the asylum. However, as Franco Rotelli says, it was necessary, it was essential to find an alternative to that violent and segregating institution, to replace it with "invented institutions." Because the end of the asylums is not the end of suffering. It is not the end of mental illness. It is not the end of the need for proximity and support for people deprived of their rights, the need to sustain them in accessing the rights of citizenship. And we needed to invent new institutions capable of achieving this goal. (Del Giudice, 2019)

In her visit to mental health services in Madrid, during one of the activities of the project, Del Giudice never stopped asking questions:

> how many beds are available in this service? Why is there a sign to ask for the lighter in the common room? ... Why the iron bars in the windows, if this is not a psychiatric ward? Far from being moral judgments, these questions about daily practices are the product of a constant interrogation of the relationship between theory and practice, a relationship that continuously reveals the contradictions and, with them, the "hidden possibilities for reproducing oppression" in daily institutional practice. (Pérez, 2019)

Maria Puig de la Bellacasa also refers to the ambivalent dimension of caring:

> To reclaim often means to reappropriate a toxic terrain, a field of domination, making it capable of nurturing; the transformative sees we wish to sow ... acknowledging poisons in the ground that we inhabit rather than expecting to find an outside alternative, untouched by trouble, a final balance – or a definitive critique ... Reclaiming care is to keep it grounded in practical engagements with situated material conditions that often expose tensions. (Puig de la Bellacasa, 2017, 11)

These contradictions are always present in the institutional mandate as a whole and in the singular competencies of each worker; they are also present in the institutional management of care as a collective endeavour. As in the practice of critique, thinking about the contradiction is not a matter of judging who or what

is right or wrong, but rather a matter of untying the contradiction in a different way each day, because the assemblage of a specific situation requires a singular approach to the problem.

Translation

In the experience of psychiatry reform in Trieste, the relationship between institutional limits and potentialities has been tested and reorganized through the radical subjectivation of technicians. This subjectivation rests upon conditions of possibility rooted in the specific history of Trieste: the process of transformation of the asylum was embedded in the Italian radical mobilizations of the 1970s, particularly through the involvement of social movements in both critique and appropriation of the institution.

This singular situation requires us to interrogate the possibilities of translating the practices and unrest of Trieste to environments and traditions that are completely different. At the same time, the questions that emerged in this radical reform of psychiatric care can interrogate social practices far beyond mental healthcare. How can we translate these questions from one site to another, from one threshold to another? How can we deal with the contradictions raised by critical institutional practices, and do so not by trying to solve these contradictions, but by being willing to *lose control* and inhabit them?

In Trieste, we found an experiment in translation beyond the limits of mental healthcare into new mechanisms of local primary healthcare services. The invention of the Health District (HD) in the late 1990s was, as Salvini puts it:

> the way the healthcare system in Trieste tried to move the practice of care from the hospital into the spatial dynamics of the city, moving technical practices as well as human resources from the institutional site to urban life, and opening the challenge of "take responsibility" of the complex life of the citizen in relation to the plural endeavour of care. There are four HD in the city, each of which tends to a population of approximately fifty thousand people, coordinating with the general practitioners and providing homecare and personalized care in the neighbourhoods through a system that uses nurses, specialists, physiotherapists, and other professionals. Outpatients' clinic, temporary care residences, rehabilitation consultancy facilities. Bursaries, targeted budgets, and social benefits are also part of the district, managed from the healthcare system in coordination with other institutions.
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> ...
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> Workers from each district follow the inhabitants when they are hospitalized. They visit the patients, follow their stay in the hospital by contacting their doctors, and

> discuss the situation with the rest of the HD staff and the patients' relatives or relevant others. At the same time, they can start mobilising the resources that will guarantee the patient's dignity and full right to health in her normal life context after she is discharged. This involves mobilising social and economic resources to support her, configuring caring and healing devices in her apartment: a thorough and safe displacement of the practice of care from the institution into social life. (Salvini Ramas, 2019)

Because institutions have a tendency to passively revert to acting like places of set rules and roles, ongoing critical work is necessary to place the institution, again and again, back into relation to the social needs and desires that legitimate its action (Deleuze, 2004). Only then from this new position will new fields of possibility open (Merleau-Ponty, 2010; Tosquelles, 1966). Translating the institution means exposing and opposing the institutional tendency to reproduce its own power, in order to reaffirm the institution itself as a social, and continuous, production.

As Franco Rotelli (1988) puts it, the role of the institutional practice is to support and guarantee the reproduction of society, not that of the institution itself. The institution should sustain users with resources in their moments of frailness, putting resources to support social reproduction (and transformation) rather than institutional reproduction (and inertial repetition). Translated beyond its own reproduction, the institution will have to invent new ways of organizing care in relation to new users, new fragilities. And this should not be a problem, but an opportunity for the institution to reinvent itself, its practices, and protocols, in relation to the life of the citizen, and to the life of the city in general.

Right to care

Thresholds, contradictions and translations are the three conceptual tools we have used so far to underlie a palimpsest of voices that affirms a new possibility of care in the urban context: at the core of our conversations and discussions was the need to rethink the 'right to health'.

> What if all these structures were properly put into value? ... What if we recreate these crossing points, this new alliance, between the designated institutions and the people? We could really imagine that the citizens constitute themselves as those who have the right to care, and that this care is a responsibility of the city: a city that cares for every single one of its citizens and by so doing, constitutes citizenship and constitutes itself as a city. (Rotelli, 2019)

When the practice of care is normalized into a fixed set of protocols, it could appear as a mere 'scientific' exercise. But all the aspects that Rotelli points out above are also part of the practice: specific politics, cultures, and power and

knowledge arrangements become objectified and fixed in the protocol (Fassin, 2000). Being conscious of that can drive another practice of care, one that is about thinking with a variety of tools, experiences, resources, kinds of knowledge, and emotions. It is about opening the threshold of the institution and getting lost in the city.

As we learned from our discussions in Trieste, the only way to defend the public system of care is by continuously transforming it; dismantling the exclusive and corporate model that institutions tend to reproduce and reorganising institutions so they support common practices of mutual care. In this sense, the right to care that we propose here is wider than the conventional understanding of the right 'to health': it is not just the entitlement of an individual to be taken care of, but our common right to care for each other. Over the course of this research, the collective dimension of health and care has gained its full meaning, prompting a formulation of the right to care as a practice of caring *with,* a practice immersed in social life. At the same time, the right to care is a challenge that continuously transforms the institution, so that care is given back to society as a common responsibility. Such a transformation is not a perpetual restructuring, as the neoliberal practice entails, but a constant upkeep and maintenance or things and relations (Berlant, 2016; Puig de la Bellacasa, 2017). In other words, the reinvention of the institution, or the repairing of the welfare infrastructure, is not a reformist exercise of institutional conservation: rather, it is a socio-technical endeavour of invention that involves both the emancipation of social agents, and the democratization of those technical knowledges embedded in the institution.

Only embedded in this institutional practice can be think about a 'right to care'. This right to care has two dimensions. The first is an urban one, where care emerges as a collective *ouvre*, as proposed by Henri Lefebvre (1991): a materialist appropriation of the right to the city that immerses the logic of rights into social milieus. If we return to Giannichedda's idea of sustaining the constitutively difficult freedom of urban life, (2005) we see now that the right to care is not about delivering a good (or bad) service; it is not about provision, but about the encounter that happens in each singular situation, and the institutional response must then emerge in accordance with it.

The second dimension is the institutional one: the reaffirmation of the institution's responsibility and the disruption of what looks like its autonomy. Affirming the right to care means opening thresholds; working with, within, and between contradictions; and conducting translations within the institution. Inventing institutions means articulating a collective practice within the institution that can sustain society in the affirmation of its own emancipation:

> The production of life and social reproduction are the practices of the invented institution; they have to avoid the narrow path of the clinical gaze, the psychological investigation, and the phenomenological comprehension, becoming instead fabric, engineering, capable of rebuilding sense, producing value and time, taking charge, identifying situations of suffering and oppression, re-entering into the social body, into consumption and production, into exchange, into new roles and new material modes of being with the other, of being in the gaze of the other. (Rotelli, 1988; reviewed translation by Salvini).

To conclude, affirming 'the right to care' allows us to imagine rights beyond a passive entitlement, as a process of collective organization. A different sustainability of institutions, always situated, always in translation.

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the authors

Francesco Salvini Ramas works at the Kent Law School. He is an activist and researcher, member of the research group Entrar Afuera and of Conferenza Permanente per la Salute Mentale nel Mondo. Recent publications include 'Space invaders in Barcelona: Political society and institutional invention beyond representation' in *Antipode* (2018) and 'Caring Ecologies' (*Transversal*).
Email: pantxorama@gmail.com

Marta Pérez teaches Anthropology at Universidad Complutense de Madrid. She also teaches a course on Mobility and Health at Duke University in Madrid. She participates in activist projects for universal and public healthcare. She is a member of the research group Entrar Afuera.
Email: marta.perez@fulbrightmail.org