The London School of Economics and Political Science

# Service-User Organisations and the Chilean Mental Health System: Tracing policy expectations and political contestations.

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A thesis submitted to the Department of Methodology of the London School of Economics and Political Science for the degree of Doctor of Philosophy, London, August 2018.

# DECLARATION

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I certify that the thesis I have presented for examination for the PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

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# ACKNOWLEDGEMENTS

The last and biggest recognition goes to my wife, colleague and best friend Nérida Mercado, for her immense generosity in accepting this challenge with me. Besides co-authoring one of the papers, she read and made comments on every draft leading of this final document. I dedicate this thesis to her, to my daughter Kika and to my son Beltrán.

# ABSTRACT

Calls for the involvement of service users and their organisations in the design, provision and evaluation of services are prominent in contemporary mental health policy discourse. Models and examples have penetrated national agendas, shaping definitions and expectations about the role and potential contribution of users. The social sciences have addressed this process, especially in the English-speaking world where service-user activism has a long history and involvement practices are well established.

Most of this literature assumes that between the goals of service user groups, family organisations and mental health authorities there is continuity. If friction arises, it is marginal in relation to a set of shared aspirations: More prevention, better services, safer treatments, etc. This approach, common in 'Global Mental Health' interventions and calls, frames participation and users' involvement as a technical decision in the hands of mental health systems. On the other hand, a critical literature, particularly based on English-speaking countries, has denounced the futility and superficiality of participatory agendas and their ability to hijack the authentic voices of users on the ground. However, the sharp distinction between a technical and a critical approach does not provide a suitable framework for the identification, description and analysis of the processes by which participation *becomes* relevant for mental health systems and the emergent self-organisation and self-differentiation of user groups.

Applying Niklas Luhmann's version of social systems theory, and drawing on interviews and participant observation with users, professionals and policymakers, this project simultaneously explores the emergence of mental health service-user initiatives in Chile and the ways in which users' participation is - and has been - approached and defined by professionals and mental health services. As an exercise of 'second-order observation', it takes a step back from the technical/critical distinction, asking how mental health systems observe the collective actions of users and how autonomous user groups organise and define themselves vis-à-vis the observation and expectations of mental health systems.

Through four independent papers, this thesis demonstrates that the way in which the mental health system defines and approaches the actions of users is less a result of their organised actions than of the changing needs of mental health policy for 'user representation', both at a broader policy level (Paper 1) and at the level of local participatory initiatives (Paper 2). Autonomous user groups, on the other hand, engage in the creation of forms

of reciprocity and meaningful action at the margins of the mental health system (Paper 3). They embrace a politics of disengagement and incommensurability that challenges the interests and problematises the situation of social researchers (Paper 4).

By adopting a constructivist, historical and reflexive approach, this thesis: highlights the role of policy shifts in determining how participation comes to be valued or devalued; puts forward an alternative approach to the political nature of users' collective actions, based on practices disengagement, rejection and incommensurability; reframes ethical and epistemological tensions between academic research and activism in the mental health field. Finally, it demonstrates that, regardless of global calls, practices of participation are shaped by local policy scenarios and trajectories.

These findings challenge the technical *implementability* of participation: although involving policy decisions and designs, participation is not *a* decision. It responds to contingent scenarios, it is subjected to complex expectations and its definition is the subject of contention by autonomous user groups.

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# PREFACE

The PhD programme at the Department of Methodology of the London School of Economics and Political Science allows PhD students to submit a paper-based thesis, a format that differs from the traditional monographic dissertation. A paper-based thesis involves an unavoidable degree of repetition across sections, particularly between the introduction and the included papers. The structure of the current thesis is as follows. The introduction (Chapter 1) explains the concrete process that led to this thesis, presents the historical and policy background of the project, reviews the relevant literature and establishes the conceptual framework for the papers. The second part (Chapter 2) includes the four papers of the thesis:

Paper 1:    Montenegro, C. R., & Cornish, F. (2017). Historicising involvement: the visibility of user groups in the modernisation of the Chilean Mental Health System. *Critical Public Health*, *0*(0), 1–13. https://doi.org/10.1080/09581596.2017.1400659

Paper 2:    Montenegro, C. R. & Mercado, N. "Making contact". Tentative engagements between institutions and communities in Chile's mental health field. (To be submitted to Social Science and Medicine)

Paper 3:    Montenegro, C. R. (2018). Beyond Participation: Politics, Incommensurability and the Emergence of Mental Health Service Users' Activism in Chile. *Culture, Medicine, and Psychiatry*, *42*(3), 605–626. https://doi.org/10.1007/s11013-018-9576-9

Paper 4:    Montenegro, C. R. "Are you a radical now?". Reflecting on the situation of social research(ers) in the context of service-user activism in Mental Health. (Under 'revise and resubmit' in Journal of Social and Political Psychology)

The conclusion of this thesis (Chapter 3) overviews the key findings of the papers, summarises its contribution to current debates in the literature and discusses the limitations of the study. After this, Annex 1 provides details about the methods used that are not included in each paper and Annex 2 includes the Ethics Review approval letter by the LSE.

# CHAPTER 1: INTRODUCTION

## 1.1 The call for service-user involvement and the origins of this project

The call for the involvement of service users and their organisations in the design and delivery of mental health services is increasingly common in contemporary mental health policy discourse. Although the roots of this orientation can be traced back to the service-user movement (Campbell, 1996) and the shift towards 'recovery' (Deegan, 1996) in countries in the global north, increasingly, user involvement has become part of a general definition of how a mental health system should work, regardless of location. A key example of this policy direction is the World Health Organization's (WHO) 'Mental Health Action Plan 2013-2020', with its explicit call for national mental health systems to empower and involve service users 'in mental health advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation' (2013, p. 10) (Saxena & Setoya, 2014).

In the English-speaking world, autonomous service-user advocacy has a long history (Campbell, 1996; Cook & Jonikas, 2002) and involvement practices are well established (Rutter, Manley, Weaver, Crawford, & Fulop, 2004). Social scientists have paid critical attention to the shifting politics of service-user involvement, its social and economic conditions of possibility and the complex, power-laden regimes of interaction and control through which participatory ideals receive administrative form (Beresford, 2010; Brosnan, 2012; El Enany, Currie, & Lockett, 2013; Rutter et al., 2004). In Latin America, on the other hand, service-user participation has only received topical attention in the context of policy plans and under the influence of guidelines and normative approaches coming from the World Health Organization (WHO) and the Panamerican Health Organization (PAHO) (Ceriani, Obiols, & Stolkiner, 2010; Kestel, 2009; Rosendo & Lincuez, 2016). With valuable exceptions (Freitas, 2011; Jorge, Ramirez, Lopes, Queiroz, & Bastos, 2008), there has been little empirical examination of the concrete administrative configuration of involvement and/or the development of user-led initiatives on the ground.

In 2013, I was part of a team evaluating the respect of human rights of service users in mental health settings in Chile, using the recently developed WHO QualityRights tool-kit (2012). Small teams of one professional and one service-user visited mental health facilities across the country for two days, to assess how users were treated using a combination of observation and interviews with patients and staff. At the end of the second day, the team had to reach a consensus, scoring each facility according to different dimensions

based on the principles of the UN Declaration for the Rights of Persons with Disabilities (United Nations, 2006).

My role was to coordinate the translation of the tool and to assist the research process in general. Chile was the third country in the world and the first Spanish-speaking nation where the instrument was used, and the agreement with the WHO was to create the official Spanish translation. The tool needed to be simple for the evaluation and interviews to succeed. Terms like 'stigma', and particularly 'recovery', were not only ubiquitous but hold an important analytical and political place in the original version, responding to specific institutional and cultural dynamics that, in our view, were absent or very different in Chile.

However, another form of absence became increasingly relevant. The tool assumed the existence of active, independent and visible user-led groups in the country, from where competent and critical users could be recruited to become evaluators, but according to members in the team, such an organisation did not exist in the country. Where could we find them? The only practical option was to recruit through mental health services, but this was not the ideal procedure according to the tool.

Gradually, through different connections and under the pressure of a rigid timeframe, the required number of users showed up to the interviews. However, these difficulties prompted a parallel discussion in the team, centred on the problem of why there were no service-user groups in Chile of the kind that the original version of the tool presumed. Why were users not a recognisable presence and voice, with known demands and forms of representativity? Intuitive answers pointed to Chile's generalised lack of a civic culture, neoliberal individualism, professionals' paternalism, etc. As the only social scientist in the team I came to be identified as someone that could at least have some ideas about this.

As part of the selection process, I interviewed different users, mostly males, aged between 25 and 50 years old, who took part in community-based rehabilitation spaces provided by NGOs. Although I had conducted research about mental health policies in the past, this was the first time that I had to engage directly and work with service users for a project. Without a clinical background, I approached this task through what I was most familiar with: qualitative interviews. Surprisingly, several of them were engaged in small organising efforts, and had a very critical view of mental health policies in the country. They told me stories of collective mobilization and sustained efforts to overcome barriers and gain autonomy. They had approached the project - and other spaces – with the intention to learn but also to share their perspectives and to shape our plans and strategies.

A different set of interrogations emerged after these encounters; interrogations that the project itself was not in a position to address. More than the reasons why users have not developed the forms of organisation and advocacy actions that the project assumed and demanded, what needed examination was the way in which users were approached and observed by health systems and authorities. Why were service users perceived in the way they were? How could the incipient collective actions of users, that I came to know through the interviews, be approached instead?

In mid-2014, a further situation confirmed my interest in researching users' emergent forms of organisation and self-representation. In June of that year, results from the second Chilean version of the WHO Assessment Instrument for Mental Health Systems (AIMS) were published. This tool was originally created 'for collecting essential information on the mental health system of a country or region' (World Health Organization, 2005, p. 1). It is applied with varied degrees of regularity in more than 100 countries and the results are the main source of information about the performance of mental health systems in low and middle income countries. The version applied in 2014 assessed the involvement of user groups 'in the formulation or implementation of mental health policies, plans or legislation' (2005, p. 55). The team that conducted the assessment was the same that developed the WHO QualityRights tool.

The results of the assessment bluntly stated that, in Chile, 'a low presence and a poor level of organisation of the mental health users and family members associations is still observed' (World Health Organization & Ministerio de Salud, 2014, p. 11). In other words, users were not present or organised in a way that could allow policy-makers to consider their views, in a way that mattered according to the main self-assessment tool of the mental health system. No information about the methodology or the kind of evidence used to support this statement was given, or a conceptual clarification about what was understood as 'presence' and what constitutes an 'adequate' level of organisation. However, beyond these methodological limitations, the statement was not surprising. It was not a discovery, it was a mere confirmation of something that was already *known*. And this refocused my project. The aim was to approach service-user groups' autonomous, collective actions beyond the regime of verification already operating in these assessments. Simultaneously, the aim was to understand the conditions of possibility of this regime. In other words, I wanted to observe the observer (Luhmann, 2012).

The present thesis reports the findings of a research project that explored both the emergence of service-user initiatives in Chile and the way

user participation is - and has been - approached and defined by professionals and mental health services in the context of recent policy transformations in the field. It draws on interviews and ethnographic fieldwork with users, professionals and policymakers. Two overarching sets of questions guided the project:

• First, how do mental health systems identify and approach the collective actions of users? How has this definition changed over time? How is an image of users' autonomous agency constructed within these systems? (Luhmann, 2012).

• Second, how, beyond this regime of legibility, do users in their current forms of organisation develop contrapuntal knowledge (Biehl & Petryna, 2013) about their own ability to act and make claims?

## 1.2 Papers included in this thesis

As indicated in the preface, this thesis includes four papers. Papers 1 and 2 address the first set of questions, exploring policy actions, reactions and constructions around service-user involvement. Considering the period between 1990 and 2005 and through oral history interviews with key policy-makers, high-level professionals, involved users, ex-users and family activists, the first paper explores the policy scenarios that have variably constituted users as a relevant public over time. Results demonstrate the existence of five overlapping and interdependent processes that shaped how user input was understood and operationalised by policy. On this basis, it is argued that the visibility and organisational potential of users have historically responded to institutional requirements external to users themselves, configuring specific forms of representation and relevance. In other words, the way in which the mental health system observes the autonomous actions of users is less a result of the actual status of user organisations than of the changing needs of mental health policy for 'user representation' and political support.

The second paper pays closer attention to the administrative complexity and fragility of 'engagement' in the absence of formalised mechanisms of involvement. Based on participant observation and interviews with policy-makers, professionals and users linked to a specific participatory initiative, the results reconstruct a temporal sequence of decisions and adjustments. In an initial move, a health service developed a network of local groups. To populate and rationalize the new network, funding was offered to local groups, and made conditional on specific formalities and the presentation of projects. A regime of meetings between local agents was established, but new problems emerged as a result of prior solutions, mobilising bureaucratic adaptations and

demanding a sense of unity and coherence among the groups composing the network. By approaching participation as a time-based, tentative phenomenon, a series of aspects defining the concrete life of participatory projects becomes visible, including a permanent and growing professional anxiety about the potential de-legitimation of their roles and decisions, and the resulting drive for control, expressed through the production of different and contradictory conditions for the participation of user groups.

Papers 3 and 4 address the second set of questions, exploring current user-led advocacy initiatives. Based on ethnographic fieldwork with an activist group, Paper 3 examines how user groups orient themselves, project themselves and sustain their own difference in the context of other agents' and systems' frameworks of legibility and approachability. The findings describe a set of circumstances that forced the group to reflect upon its own value vis-à-vis the requirements and expectations of the legal system, the mental health system, and wider society. In the face of these expectations, the group developed a sense of itself and an ability to dispute its own definition. Drawing on Jacques Rancière's theorisation of 'police order' and 'politics' (1999), the notion of a 'politics of incommensurability' is proposed to thread together a reflexive rejection of external definitions and the development of a sense of being 'outside' of the mental health system and its publics.

Finally, drawing on the ambiguities surrounding my own role as observer across activist initiatives, and following the call for strong reflexivity in qualitative social research (Kuehner, Ploder, & Langer, 2016), Paper 4 retrospectively traces how my interests and presence were received, negotiated and contested by users and non-users in the field. The results describe four episodes in which my own status - and that of other researchers - was interrogated and the efforts I made to articulate and legitimate my interests and presence in the field. In the conclusions, I discuss the analytical value of reflexivity in researching activism and the limits of a normative call for a political and ethical alignment between activists and researchers, especially in the context of emergent practices in the global south.

This research project is the first exploration of the emergence of service-user activism and the politics of involvement in Chile. It demonstrates how, regardless of global calls, notions and possibilities of participation are shaped by local policy trajectories, contributing to debates about global/local dynamics in mental health policy. It provides a historical and constructivist account of how participation and, especially, 'representation' is shaped, and suggests an alternative understanding of the self-differentiation of users, focused on concrete practices of disengagement and rejection. Finally, it

contributes to ethical and epistemological discussions about the relationship between academic research and activism in the mental health field.

The following section introduces the development and main characteristics of the Chilean mental health system and describes the limited participatory mechanisms available for service-user. Subsequently, the international literature on service-user involvement and autonomous organising practices is reviewed to explore potentially fruitful avenues, and to identify limitations in relation to the Chilean scenario. Finally, the specific theoretical framework for the thesis is proposed in order to reconceptualise the research questions.

## 1.3 Chilean Context

In this section, the main elements defining the current status of mental health policy in Chile are explained in order to situate this research project. Most of the contents of this section overlap with the contextualisation offered in each individual paper. Therefore, this is a concise introduction that traces the broader scenario for the four pieces.

### 1.3.1 Mental health policy and the role(s) of users

As in the rest of Latin America, the asylum constituted the dominant institutional response to those deemed 'mad' for most of Chile's history as an independent country (Conti, 2011; Minoletti, Rojas, & Sepúlveda, 2010). For nearly all of the twentieth century, psychiatry operated as a closed field and through four public asylums, halfway between penal and medical institutions (Minoletti et al., 2010). In the wake of deinstitutionalisation in Europe and North America, a series of alternatives were explored by some pioneering psychiatrists, most notably the 'Intracommunity Psychiatry Program' developed by Juan Marconi in the south of Santiago in 1968 (Marconi, 1972), inspired by the deinstitutionalisation process led by Franco Basaglia in Trieste and the 'Movement of Community Psychiatry' in the USA (Maass, Mella, & Risco, 2010; Scheper-Hughes & Lovell, 1986).

Dictatorship meant the sudden end of these experiences (Mendive, 2004) and, between 1973 and 1989, the main instrument of support and containment for psychiatric patients was, again, the asylum (Sepúlveda et al., 2012). In parallel, the military regime enforced a new neoliberal constitution that opened public services (including health) to market forces, while maintaining an underfunded public sector for the poor. By the end of dictatorship, the mental health budget, itself 1% of the total health budget, was

concentrated in four understaffed and overcrowded psychiatric hospitals (Minoletti et al., 2010).

In 1990, coinciding with the end of dictatorship in Chile and other countries in the region, the 'Conference for the Restructuring of Psychiatric Care in Latin America' was celebrated in Caracas, and the ensuing Caracas Declaration was signed by all ministers of health of the Americas (Bolis, 2002). The Declaration outlined a series of principles of modern mental health, the most important of which was the reduction of funding for closed psychiatric hospitals and the creation of community-based alternatives. Besides, it highlighted the need to make mental health services available through normal health settings - especially primary care - and called for the development of legal safeguards for the respect of the human rights of patients (Saraceno, 2007). These principles served as a foundation for the first and second National Mental Health Plans in Chile (Minoletti & Zaccaria, 2005).

After the Declaration, two distinct policy paths can be distinguished in the region. Countries such as Brazil and Argentina deepened sub-local reform processes that preceded Caracas, while Chile, Cuba and others prioritised the general integration of mental health into primary health and a strong centralisation of policy development (Maass et al., 2010). In Chile, this was reflected in the first National Mental Health Plan of 1993. Despite these efforts, by the end of the 1990s, deinstitutionalisation was stagnated, with only partial and uncoordinated community-based alternatives. Mental health as a whole still had a low priority within the health sector (Minoletti, Sepúlveda, & Horvitz-Lennon, 2012).

To address this, the mental health authorities in the Ministry of Health gathered a broader support base for the creation of a Second National Mental Health Plan, including human rights lawyers, NGOs, mental health professionals and family organisations. CORFAUSAM, the National Coordinator of Organisations of Families, Users and Friends of Persons with Mental Disorders, was created in this context. Active service users within CORFAUSAM pushed for the creation of a user-led organisation, and the National Association of Mental Health Service Users (ANUSSAM) was born in 2001, a process documented in Paper 1 (Montenegro & Cornish, 2017).

In a parallel development, across the 1990s, the Chilean state introduced a set of norms aimed at fostering local community organisation and participation in public services. In 2011, the Law 20500 'On Associations and Citizens' Participation in Public Administration' was promulgated, institutionalising a series of mechanisms of participation (Ministerio Secretaría General de Gobierno, 2011). Within the health sector, these mechanisms included the 'Local Development Councils' (CDL for their initials in Spanish)

or users' councils, representing the visions and opinions of the community in each health service at the local level. Other mechanisms defined by this law and partially implemented within the health system are the Participative Public Accounts, where local health authorities inform the community about financial and clinical performance within a given time, and the Citizens' Dialogues, a yearly event where organised users and health authorities meet to discuss issues of common concern. The influence that users can exert through these mechanisms is limited (Méndez & Vanegas López, 2010; Rubio & Ugarte, 2012). More importantly, these mechanisms are generally absent in mental health services (Minoletti et al., 2015).

### 1.3.2 Activism within and outside the mental health system

When service users are given a role in policy documents and other studies, it is usually assumed that their interests are continuous with the long-standing 'progressive' aims of authorities, professionals and family groups (Montenegro & Cornish, 2017), such as the development of community-based alternatives, the increase in mental health funding and, more recently, the struggle against the stigma attached to mental illnesses (Ceriani et al., 2010; Zaldúa et al., 2012). However, during recent years a will to self-differentiation (addressed in Paper 3) has characterised the actions of user-led groups (Montenegro, 2018).

Two distinct processes are at the origin of this transformation. The disability rights movement has seen its influence and support grow over the last few decades, particularly after different Latin American states signed the Convention for the Rights of Persons with Disabilities (Angel-Cabo, 2015; Figueroa, 2017; United Nations, 2006). In Latin America, since the early stages of deinstitutionalisation, long term mental health problems have been framed as psychosocial disabilities (Chuaqui, 2007). The vocabulary of rights has played a key role in mental health advocacy since the 1990s (Minoletti et al., 2015; Montenegro & Cornish, 2015; Observatorio de Derechos Humanos de las Personas con Disacapacidad Mental, 2014), serving as a platform for the articulation of different advocacy efforts.

In parallel, a burgeoning 'anti-psy' scene has emerged, particularly within academic psychology, through the work of Chilean philosopher Carlos Pérez-Soto (2012) and the critical community psychology of Domingo Asún and others (Domínguez, Kornblit, Rovira, & Asún, 2002). Their work interpreted and mobilised a sense of exasperation about the role of psychological knowledge and techniques in the consolidation of neoliberal policies in the country (Castillo, 2015). These ideas resonated with the political values and

collective practices of many students who have participated in different waves of protest sweeping the country over the last decade (Cabalin, 2012).

To summarise, service-user involvement has had a timid presence in policy definitions and plans during the last few decades. Although ANUSSAM is an active organisation, its range of action has been limited (Montenegro & Cornish, 2017). Available participatory mechanisms within the health system have not reached mental health services. Outside the mental health field, advocacy platforms have emerged, organised around the notion of psychosocial disabilities and human rights under the influence of the Convention for the Rights of Persons with Disabilities, connecting with academic 'anti-psy' discontent. This sets the stage for an analysis of how professionals and policy makers understand and value service-user involvement, and for a closer examination of emergent forms of involvement and activism by users. Before that, in the next section, the main approaches in the literature towards service-user involvement will be reviewed.

## 1.4 Service-user involvement and activism. A review of the literature

The papers in the findings section of this thesis include a review of the relevant literature and a succinct description of their guiding theoretical frameworks. The aim of the current section is to unpack the different strands of research on service-user involvement and activism developed over recent years that are relevant to the objectives of this thesis, including elements that, for reasons of space, could not be included in each paper. Following the broad division of the thesis, the first subsection deals with the idea of 'involvement'. It begins by describing the way this idea has been used and promoted within mental health systems and services, and then reviews the approaches from the social sciences. The second subsection deals with the idea of service-user activism, as an independent social movement. Finally, the limitations of these approaches for the analysis of incipient participatory and organisational practices are considered.

### 1.4.1 Service-user involvement and participation: Main approaches

From a focus on the clinical or therapeutic value of empowerment and involvement, to critical concerns about issues of power and co-option, the idea of service-user involvement and participation is fraught with tensions and ambiguities (Stewart, 2013, 2016). Barello et al. provide a useful categorisation of the way involvement is conceived in health interventions, based on 259 articles written between 2002 and 2013 (2014). In their review, within the mental health literature, involvement is mainly viewed as clinical

alliance, and used as a tool to obtain better clinical outcomes (Barello et al., 2014; Horrocks, Lyons, & Hopley, 2010). Addressing the limitations of this view, but still centred on individual processes, other authors frame involvement as an aspect of 'recovery', understood as a personally defined path towards self-realisation and wellbeing (Brown, 2012; Storm, Hausken, & Mikkelsen, 2010). From these perspectives, 'involvement' accompanies, enriches and forms part of a therapeutic process.

Tabuzyer, Pieters and Van Audenhove (2013) distinguish three levels of user involvement in mental health care: the micro level of individual patient-doctor encounters, the 'meso' level of institutions and services and the macro level of policy, the latter including autonomous user organisations. The move from individual involvement in a therapeutically defined process towards collective influence in policy is assumed to be a progression across stages, following Arnstein's classic ladder of participation (1969).

These approaches - and most of what counts as a 'recovery' paradigm in mental health services delivery - assume the existence of an unobtrusive space where users, at an individual or collective level, can control their treatments and the policies affecting them (Harper & Speed, 2012). In contrast, many authors have insisted on the fundamental asymmetry that defines the relationship between service users and providers, particularly in the mental health field (Carr, 2007; Lewis, 2014). Involvement practices respond to contingent policy requirements that have not transformed this asymmetry (Barnes, 1999; Beresford, 2010; Brosnan, 2012; Lewis, 2009, 2014).

Pilgrim states that while 'the voice of users has been asserted, the voice of consumerism has been elicited' (2005, p. 24). He points to the active role of the mental health system in framing – and limiting - the engagement of users. This has been described as incorporation (Forbes & Sashidharan, 1997), professionalisation (El Enany et al., 2013) and, encompassing all such expressions, co-option (Pilgrim, 2005).

In discussing co-option, Pilgrim emphasises the position of power from which involvement is promoted. This resonates with Gaventa's contention that 'simply creating new institutional arrangements will not necessarily result in greater inclusion' (2006, p. 26). This is particularly relevant considering the global call for users involvement and the idea that national health systems should foster and empower user groups. The prospect of returning power to users' depends on a critical examination of how power is already expressed across and within institutions. As Tomes notes, 'In the mental health field (…) consumers' interests tend to be the least well organised and most underfunded. Their input has been welcomed and acted on only to the extent

that it serves the purposes of other, better-organised stakeholders' (2006, p. 725).

Harrison & Mort introduced the idea that users' involvement in health care should be understood as a 'social technology of legitimation' (1998). The 'user card' is variably played by professionals to give themselves and their ideas legitimacy and to retain, at the same time, an ability to dismiss the concerns and demands of users by reference to their un-representativity - in relation to an abstract universe of other users- or their informality as organisations (Martin, 2008b, 2008a).

More recently, El Enany, Currie and Lockett have studied the mechanisms by which the mental health system safeguards its own boundaries 'through a combination of self-selection by those wanting to be involved, and professionals actively selecting, educating and socialising certain users' (2013, p. 24). By carefully observing a specific participatory project in the UK, they show that the process of selection of users carried out by professionals and managers induces an alignment of perspectives and limits the expression of conflict. Their findings are in line with recent studies pointing to how users' perspectives are 'defused' and 'sanitised' in the context of participatory initiatives (Komporozos-Athanasiou, Fudge, Adams, & McKevitt, 2016; Renedo & Marston, 2015). These approaches frame involvement and participation as strategies firmly held within the boundaries of mental health systems.

*1.4.2 Service-user activism: Main approaches*

The autonomous organisation of service users and the processes through which they develop a collective identity outside the limits of the mental health system have been the object of several studies over the last decades. Barnes' and Bowl (2001) see in the initial damage done by traditional psychiatric services, the main motivation for activism. The attachment of a psychiatric label imbues persons in a dynamic of submission to others' decisions. Subsequently, users are seen as unable to control their own lives, and treatments are forced on them 'for their own good' (2001, p. 7). Distress itself interacts with structural sources of exclusion activated by the psychiatric label, undermining the position of users on three levels: 'in their interpersonal relationships, in their relationships with the mental health system and in their position as citizens within the communities in which they live' (Op. Cit. p 17). How do users manage to escape this circle?

The classic studies of Thomas Scheff regarding the identities of psychiatric patients led him to conclude that, once internalised, the psychiatric

label is reinforced in his social milieu, closing any space for an alternative self-definition (1966). Against this view, Morrison traces the ways in which users have been able to collectively overcome the power of diagnosis (2005). For her, social scientists need to rethink their own premises and produce adequate conceptualisations of resistance that address the process by which people move from 'a "sick role" identity of "mental patient", with all that entails, to the tertiary phase in which the crazy identity was claimed, re-defined, and championed by its carriers' (2005, p. 12). This thesis takes up this challenge, with the added dimension of a mental health system that seems equally unable to recognise such resistance.

For Morrison, a key historical element in this transition - in an Anglo American context- is the possibility of disagreement about medical interventions, the growing availability of options and other changes introduced in the delivery of mental health services over the last few decades in the west, where control has passed from the professional to the 'consumer' (2005, p. 13). This process is reinforced by the emergence of self-help alternatives, which not only provide support and reciprocity but also a space to share and validate forms of 'experiential knowledge' (Borkman, 1976). This, in turn challenges the role of professional authority.

In the UK, Peter Campbell, a service-user and activist, identifies two major processes underlying the emergence of self-advocacy initiatives by mental health users (1996). First, deinstitutionalisation allowed a minimum degree of freedom to engage in conversation with peers outside hospitals, discussing experiences and developing self-help practices. Influenced by the civil rights movement, these groups embraced the idea of self-determination (Cook & Jonikas, 2002). Deinstitutionalisation was also accompanied by a generalised discredit of psychiatry and, within this process, a multiplication of professional identities consolidating their stake in the field, creating new opportunities for users to be heard (Castel, Castel, & Lovell, 1982).

Anti-psychiatry holds a problematic position vis-à-vis service-user activism (Campbell, 1996; Crossley, 2006). On the one hand, the insistence on the meaningfulness of extreme states such as 'psychosis' dignified and gave relevance to the experiential accounts of users. However, the concrete organisation of user groups took a different orientation, partly because the 'anti-psychiatry' label diminished their ability to participate in the necessary transformations of the mental health field. As Campbell states, the user-movement relationship with anti-psychiatry 'has been emotional and spiritual rather than programmatic and practical' (Campbell, 1996, p. 221).

A final contextual factor highlighted by Campbell is the consumerist turn that shaped the health sector in England through the 1980s (Campbell, 1996;

Clarke, 2007; Milewa, Valentine, & Calnan, 1999). Regardless of its neoliberal affinities, consumerist ideology forced services to hear what users had to say (Campbell, 1996). This was not a deep democratisation of the mental health system but afforded opportunities for users to be regarded as a group with clear, consistent and challenging views; a group able to exercise 'reflective choice' (Tovey, Atkin, & Milewa, 2001). The notion of involvement as an 'ethical requirement' of health-care systems came out of this specific ideological and institutional milieu (Tambuyzer, Pieters, & Van Audenhove, 2014).

Primarily based on English-speaking countries - where most of the literature about service-user organisation and activism comes from - these studies examine patterns of organisation and activism with a relatively long history. They provide rich descriptions and conceptual frameworks that can serve as points of reference to understand the Chilean situation. However, in general, they see user collective actions as always at the risk of being manipulated and co-opted by the mental health system, and this is related with the history of the movement in *that* context.

The challenge for this research project is to find a conceptualisation of power and resistance that can be adapted to the specific politics of service-user activism in a new context, one in which positions and engagements are in the making, where a vague notion of the role users is emerging, but where official assessments deny their relevance. In the next section, the limitations of the literature are further discussed and the theoretical framework of the thesis is presented. Subsequently, the research questions are reformulated with the help of this conceptual scheme.

## 1.5 Theoretical framework for the thesis

Beyond the different emphasis, in general the reviewed literature on service-user involvement and activist practices assumes a fundamental opposition between those who co-opt and those being co-opted, an opposition generally framed through the distinction between life-world and system (Habermas, 1984), common in many approaches to the interaction between health systems and communities (Gibson, Britten, & Lynch, 2012; Lo & Bahar, 2013; Scambler & Kelleher, 2006). Following the work of Hutta in his exploration of the LGBT movement in Brazil, identifying agents and positions across some version of this distinction ultimately displaces 'the paradoxes that ensue from the dynamic coexistence of heterogeneous positions and engagements' (2010, p. 150). Without denying the existence of power asymmetries and the concrete disadvantage with which service users approach participatory spaces, the emergent nature of participation and

activism in this field means that the boundaries defining groups and interests are not clear.

More generally, 'the transposition of paradoxes into a normative politics of oppositions and contradictions' (Hutta, 2010, p. 144) dominates what has been termed the 'classical' approach to public involvement in health (Contandriopoulos, 2004) based on a normative definition of what participation should be and on an implicit standpoint regarding its desirability. The theoretical task for this thesis is to articulate a framework in which the distinctions that dominate the conceptualisation and practice of involvement, either coming from agents such as the WHO or from the local policy makers, can be, in turn, observed; a framework that facilitates the observation of the distinctions used by the mental health systems to create an image of users and their agency, both in biomedical or in policy terms, and that simultaneously allows for the exploration of how users situate themselves vis-à-vis this observation. This framework of observation is provided by Niklas Luhmann's Social Systems Theory.

### 1.5.1 Niklas Luhmann's Social Systems Theory

When we discuss involvement, we need to address the multiple ways in which the idea is defined and acted upon, by different groups over time and across places. In the context of social systems theory's radical constructivism, the coexistence of multiple ways to see the world is a fundamental aspect of modern society. Following the arguments deployed earlier, the aim of this project is *to approach* the way involvement *is approached*, identified, acted upon and stabilised in a specific policy domain. In Luhmann's terminology, the aim is to *observe observations*, something he defines as Second Order Observation (1995), a perspective that 'enquires about the blind spots of society and of the systems of society, about the distinctions that fundamentally decide what can appear in society and how' (Andersen, 2003, p. 65). Before defining more precisely what second order observation is, we will briefly develop the main elements of Luhmann's theory of society to situate the idea in its specific conceptual background.

### System and Environment

The main concept associated with the name of Luhmann is that of 'system' or 'social systems'. However, the notion of system should not be taken as a sign of rigidity. Luhmann uses the idea of system because, for him, it is better suited to overcoming a traditional sociological focus on societal integration, that can be traced back to Durkheim (1973) and Parsons (2013).

Luhmann places the emphasis on how modern society develops through *differentiation* of increasingly specific functional realms such as the law, economics, politics, etc. (1995). Systems are the form that this differentiation takes.

The difference between system and environment is of crucial importance in this regard. In a very abstract and succinct definition, for Luhmann 'a system *is* the difference between system and environment' (2006, p. 38). Systems are not defined by what they contain but by how they differentiate themselves from an *outside.* For Luhmann, they do this by *observing* on the basis of a specific distinction expressed as a binary code. The legal system uses the code lawful/unlawful to differentiate a world that is relevant for itself (Luhmann, 2004). The system exists only on the basis of the permanent actualisation of this distinction. The distinction holds together everything that comes to be part of the legal system, and, for Luhmann, the same is true for the political system (Luhmann, 2016), art (Luhmann, 2000), religion (Luhmann, 2013) and more. What is important is that, through their own operations, social systems distinguish themselves from their environment and, in doing so, they are guided exclusively by their own distinctions: their own ways of seeing the world.

There are no normative ambitions in this view of society. Unlike Parsons, Luhmann is not worried about the potential disintegration of society. Each functional realm - law, economy, politics, etc. - is the result of blind evolutive drives, forms of adaptation to increasingly complex conditions that are indifferent to any call or effort towards integration. In other work, Luhmann proposes the idea that the difference between system and environment is a difference between levels of complexity (1989). The environment *is* the complexity that the system is still not able to *read* with its own guiding code. However, the starting point is not the system or the environment but the distinction between them, whose form includes them both. Only in relation to one another can system and environment emerge. What is important is that the distinctions and selections that a system makes are rooted in its own operations, in its internal - and contingent - transformations. 'The coherence of a system depends upon its ability (over time) to differentiate itself from, but also to engage with and *interpret,* its environment in terms of its code of organization' (Daly, 2004, p. 10).

*Systems and observation*

Social systems create themselves *autopoietically* by distinguishing themselves from their environment and then by using this distinction to observe (Luhmann, 1995). As Luhmann states 'Meaningfully operating

systems reproduce themselves in ongoing implementation of the distinction between self-reference and other-reference' (2012, p. 40), the distinction between what they are and what they are not. However, and this is crucial for the aims of this thesis, the observations that produce the system are blind to the distinction that made them possible. This connects us back to the initial remarks about second order observation. If systems constitute themselves by operations of observation that are based upon the difference between self-reference and other-reference, then a secondary form of observation can be produced, one that is able to observe what the initial observation had to leave aside in order to observe. As Gershon explains, 'distinguishing between system and environment, or distinguishing whether something is right or wrong, legal or illegal, beautiful or ugly – all are first-order observations. Observing this distinction – noticing the initial separation or categorization – is a second-order observation' (2005, p. 101).

As Andersen notes, in trying to formulate systems theory as a theory of observation, 'the world does not ask to be observed in a particular way. The world is what it is. **But what is of interest is the way the world comes into view and how this affects the way we interact with it'** (2008, p. 12 emphasis added). This is the main theoretical principle that guides this thesis. Boiled down to its most fundamental characteristic, 'participation' is a process by which institutions approach something that lies outside of them. This process requires a definition of what is outside; why it is relevant and how it can be approached. What systems theory adds to this is the recognition that when a system approaches and observes something, it does so through itself, guided by its own requirements and logics. And what second order observation adds to this is the idea that the social sciences can observe the processes that determine how a system observes.

Although other authors from different traditions are introduced across the papers included the following section- most notably Jacques Rancière's work on police and politics for the interpretation of service-user activist practices - Luhmann's social systems theory provides the broadest conceptual framework for this thesis. This theory allows for the observation of how mental health systems *as systems* deals with users (and other publics) in specific ways, and according to certain orientations and goals that are meaningful to them. Users and their collective endeavours are radically outside, unless their complexity becomes organised according to the constitutive principles of the system itself. While empirical studies have demonstrated the centrality of processes of selection in the 'domestication' of user actions within health systems (El Enany et al., 2013; Renedo, Komporozos-Athanasiou, & Marston, 2017) systems theory provides a broader framework to pursue further analysis.

## 1.6 Research questions

Guided by this framework, the invisibility of users should be understood as a result of the operations of the mental health system, operations expressed in observations that are oriented by distinctions that this project attempts to unveil. On the basis of this theoretical discussion and articulation, the research questions can be rephrased as:

• First, what are the processes that underlie the way the Chilean mental health system has come to observe and approach the reality of service-user organisations and the meaning of service-user involvement? How has the image of user groups changed over time and in relation to what transformations in the mental health system?

• Second, how do autonomous user collectives organise and define vis-à-vis the observation and expectations of mental health systems? How do they distinguish themselves from the image created by these systems?

In the following section, the methodological approach and the process of data collection of the thesis is described (further methodological details are also provided in Annex 1).

## 1.7 Methodology

The papers included in the findings contain their own methodological section specifying the techniques, strategies and main methodological decisions, analytical approach and ethical considerations used in each case. Added detail is provided in the Methods' Annex (Dunleavy, 2014), in page 154. Paper by paper the annex includes the topic guides for interviews, list of interviewees, coding frameworks, a description of the settings in which participant observation was conducted and relevant information that is not present in each paper.

# CHAPTER 2: PAPERS

## 2.1 Overview

This section contains the four papers composing this thesis. Papers 1, 2 and 3 are traditional empirical papers. Paper 4 is a reflective piece in which I draw on fieldwork experiences to retrospectively trace how my interests and presence were received, negotiated and contested by service-user activist groups. Authorship and editorial details of each paper can be found bellow.

Paper 1:     Montenegro, C. R., & Cornish, F. (2017). Historicising involvement: the visibility of user groups in the modernisation of the Chilean Mental Health System. *Critical Public Health*, *0*(0), 1–13. https://doi.org/10.1080/09581596.2017.1400659

Paper 2:     Montenegro, C. R. & Mercado, N. "Making contact". Tentative engagements between institutions and communities in Chile's mental health field. (To be submitted to Social Science and Medicine)

Paper 3:     Montenegro, C. R. (2018). Beyond Participation: Politics, Incommensurability and the Emergence of Mental Health Service Users' Activism in Chile. *Culture, Medicine, and Psychiatry*, *42*(3), 605–626. https://doi.org/10.1007/s11013-018-9576-9

Paper 4:     Montenegro, C. R. "Are you a radical now?". Reflecting on the situation of social research(ers) in the context of service-user activism in Mental Health. (Under 'revise and resubmit' in Journal of Social and Political Psychology)

As stated in the preface (page 9) Paper 1 is co-authored with Professor Flora Cornish and Paper 2 is co-authored with Nérida Mercado. I contributed 75% to Paper 1 and 80% to Paper 2.

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RESEARCH PAPER

# Historicising involvement: the visibility of user groups in the modernisation of the Chilean Mental Health System

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## Abstract

In western mental health systems, the involvement of user organisations has become an important dimension of contemporary policy development. But the processes constituting users as a relevant/irrelevant group have received little investigation, especially outside the English-speaking world. Drawing on Luhmann's theory of society, this article presents a reconstruction of involvement initiatives in mental health policy in Chile between 1990 and 2005. It is based on 17 oral history interviews with policy-makers, high-level professionals, involved users, ex-users, and family activists, drawing also on relevant policy documents created during this period.

Five processes are identified. In the early 1990s, the relevance of family groups as care providers in the context of deinstitutionalisation shaped the first encounters between psychiatry and community. Later, user groups became relevant as political supporters of the Mental Health Department's funding requests, and in their capacity to legitimise decisions on involuntary treatment. The first National User Organisation resulted, in 2001. Its relevance was quickly undermined, however, by a health reform which restricted the definition of diseases and treatments with reference to evidence and costs. The legitimation of users was no longer needed and efforts to involve them subsided.

Thus, we argue that the way in which the mental health system observes the voices of users is less a result of the actual status of users' organisations than of the changing needs of mental health policy for 'user representation'. By highlighting the contingency of policy shifts, we suggest that this historical and systemic perspective provides grounds for the strategic irritation and transformation of mental health systems through users' activism.

## Introduction

*Chilean Mental Health Policy and the role of users*

For most of Chile's history, the asylum constituted the dominant institutional response to those deemed 'mad'. The creation of the National Health Service in 1952 increased the reach of services, but psychiatry was still understood as a legal/penal field (Minoletti, Rojas, & Sepúlveda, 2010). From the late 1950s to the early 1970s, coinciding with a strong condemnation of the living conditions of psychiatric inmates, alternative approaches were explored throughout Latin America, following Franco Basaglia's deinstitutionalisation process in Trieste and the 'Movement of Community Psychiatry' in the USA (Maass, Mella, & Risco, 2010; Scheper-Hughes & Lovell, 1986).

The military coup of 1973 and the ensuing 30 years of dictatorship destroyed the incipient community-based experimentation and the psychiatric hospital regained its monopoly. Meanwhile, radical neoliberal reforms divided the health system into a small private sector and a poor and overcrowded public sector (Missoni & Solimano, 2010). By the end of the dictatorship, four mental hospitals consumed most of the mental health budget. People were locked in overcrowded institutions, without opportunities for rehabilitation or social inclusion, and subjected to human rights violations (Minoletti et al., 2010). The return of democratic institutions ignited a series of reforms guided by the 'Conference for the Restructuring of Psychiatric Care in Latin America' and its 'Caracas Declaration', signed by most countries in the region in 1990. Subsequently, a long overdue process of deinstitutionalisation and decentralisation began (Caldas de Almeida, 2005).

Two distinct policy paths followed the Declaration. Countries such as Brazil and Argentina promoted deep reforms and experimentation at the local level, while Chile, Cuba and others prioritised the integration of mental health into primary health (Maass et al., 2010). In Chile, this was reflected in the first National Mental Health Plan of 1993. Despite these efforts, by the end of the 1990s deinstitutionalisation was stagnated, with minimal community-based alternatives and Mental Health still low-priority within the health sector (Minoletti, Sepúlveda, & Horvitz-Lennon, 2012).

In this context, the new Mental Health Department (MHD) within the Ministry of Health aligned new sources of support for its Second National Mental Health Plan. A network of civil society actors developed, including human rights lawyers and advocates, NGOs, mental health professionals and family organisations. This process gave birth in 1999 to CORFAUSAM, the National Coordinator of Organisations of Families, Users and Friends of Persons with Mental Disorders. The idea of a user-led advocacy organisation with national representation began to take shape, born out of users' activism within CORFAUSAM. Finally, the National Association of Mental Health Service Users (ANUSSAM) was created in 2001.

In 2000 the Second National Mental Health Plan was published, consolidating the first plan's main goals, raising the budget of mental health, relocating services from psychiatric wards to decentralised units and improving the macro-organization of the system as a whole (Minoletti & Zaccaria, 2005). In 2005 the AUGE reform was signed, which aimed to expand health coverage by prioritising a delimited set of health problems, and defining the authorized treatments, waiting times and statutory rights of patients (Dannreuther & Gideon, 2008). Among 69 diseases, three mental health diagnoses were included: Schizophrenia, Depression and Problematic Substance Abuse. This was to have a specific impact on the interaction between ANUSSAM and the Mental Health Department.

Unlike Argentina or Brazil, whose advances in mental health policy have privileged subregional experimentation and differentiation (Alarcón & Aguilar-Gaxiola, 2000), Chile has followed WHO's technical recommendations carefully before and after the Caracas Declaration. Its gradual deinstitutionalisation process and the sustained scaling-up of services have been promoted as a model for other countries in the region (Araya, Alvarado, & Minoletti, 2009). Nonetheless, and although ANUSSAM has been functioning formally since 2001, the latest version of the WHO Assessment Instrument for Mental Health Systems (AIMS) concludes that, in Chile, 'a low presence and a poor level of organisation of the mental health users and family members associations is still observed' (World Health Organization & Ministerio de Salud, 2014, p.11).

This article uses oral histories to examine the processes that preceded, influenced and accompanied the creation of ANUSSAM in order to historicise the visibility of users, and understand how the Chilean mental health field has produced the conditions for this observation of a 'poor' state of user organisations.

*User organisations and the mental health system.*

The collective agency of users and their ability to influence policy has been differently conceptualised and justified in the psy-sciences, the social sciences and by users/survivors themselves. Speaking from a user perspective and in the UK context, Peter Campbell (1996) identifies two major processes explaining the emergence of self-advocacy by mental health users. First, deinstitutionalisation allowed a minimum degree of freedom to engage in conversation with peers outside the hospital, discussing experiences and developing self-help practices. Influenced by the civil rights movements, these groups embraced self-determination and political activism (Cook & Jonikas, 2002). Critiques of psychiatry gained currency, and there was a multiplication of professional groups claiming a stake in the field (F. Castel, Castel, & Lovell, 1982), bringing new opportunities for users to be heard.

Second, the consumerist turn shaping the health sector in England and other Anglo-Saxon countries through the 1980s and 1990s (Milewa, Valentine, & Calnan, 1999) forced services to hear what users had to say (Campbell, 1996). This was not a deep democratisation of the mental health field, but afforded opportunities for users to be regarded as a group with consistent and challenging views (Tovey, Atkin, & Milewa, 2001).

The market-based approach to the engagement of users has been the subject of several critiques. Pilgrim claims that while 'the voice of users has been asserted, the voice of consumerism has been elicited' (2005). He is pointing to the active role of the mental health system in framing and, fundamentally, controlling the nature, scope and results of the engagement of users. This process has been described as 'incorporation' (Forbes & Sashidharan, 1997) and 'co-option' (Pilgrim, 2005). As Tomes notes, 'In the mental health field […] consumers' interests tend to be the least well organised and most underfunded. Their input has been welcomed and acted on only to the extent that it serves the purposes of other, better-organised stakeholders' (2006, p.725).

While this line of analysis validly emphasises the power imbalances limiting the nature and outcomes of participation, it tends to overemphasise the domination of institutions and their rationality. Other authors have sought to unpack concrete instances of involvement in their contingent policy scenarios. El Enany, Currie and Lockett analyse the mechanisms by which the mental health system has adapted itself to 'involvement', safeguarding its own boundaries 'through a combination of *self-selection by those wanting to be involved* [emphasis added], and professionals actively selecting, educating and socialising certain users' (2013, p.24). Martin (2008)

considers representativeness as a negotiated outcome of concrete attempts at engagement, situated in specific policy contexts, beyond the abstract 'interests' each side represents. This literature points to how patterns of selection and representation cut across the boundaries of institutions and user groups, complicating a stable model of positions and interests (Hutta, 2010; Lauritzen, Salomo, & La Cour, 2013). We follow this analytical line to examine how users, their goals and organisational potential have been framed in policy, and how this framing is rooted in the transformations of the mental health system over time.

To do so, we draw on Niklas Luhmann's theory of society and particularly his twin notions of observation and distinction (Andersen, 2010; Luhmann, 1995, 2012). In this approach social entities and processes are the results of forms or 'distinctions' used to observe them. More specifically, in modern society different subfields (economics, politics, art, etc.) gain increased functional differentiation and the ability to observe other social systems and society as a whole through different distinctions adapted to their own self-reproducing requirements (Luhmann, 1995). In the context of our discussion this means that the organised agency of users is filtered by the mental health system through selective patterns of attention or relevance. Observation is an operation occurring *in* the system (Luhmann, 2006), meaning, in our case, that those patterns are rooted in the mental health system's own complexity and its contingent and dynamic relations with other systems (legal, economic, etc.). The observations made by the mental health system serve to maintain and reproduce that system.

While abstract, this conceptualisation closely matches the notions of selectivity and legitimation already present in empirical analyses of participatory practices in mental health systems (El Enany et al., 2013; Harrison, Barnes, & Mort, 1997; Harrison & Mort, 1998), situating them in a broader sociological theorisation. In this sense, selectivity becomes one expression of how systems observe on the basis of distinctions, in a recursive, self-referential way: Present distinctions are based on prior distinctions and form the basis for further distinctions upon which observation become possible.

In this article, the relation between users' organisations and the mental health system is conceived as a temporal process of selectivity and observation embedded in broader institutional transformations. The analysis is focused on those contingent policy scenarios that shifted the relevance of user organisations and their input. This is done in order to understand how certain policy processes, within and outside the mental health field, have configured a particular relation between the mental health system and users'

organising efforts, affecting the distinctions through which those efforts are observed.

## Methods

There exists no written history of users' self-advocacy in Chile. Users are absent from the available historical treatments of psychiatry and mental health policy (Marconi, 1999; Minoletti et al., 2010). In this article, we follow the principles of oral history, pragmatically formulated as 'the interviewing of eye-witness participants in the events of the past for the purposes of historical reconstruction' (Grele, 1996, p.63). According to Perks & Thomson, a distinctive contribution of oral history is to include 'the perspectives of groups of people who might otherwise have been hidden from history' (1998, p.ix). Mental health service users are one such group.

### Selection

Seventeen interviews were conducted between July and December 2015, with actors centrally involved in the creation of ANUSSAM in 2001. A snowball sample was initiated by approaching five participants known to the first author, across policy and user-led initiatives. Nine authorities and professionals working and/or directly collaborating with the Mental Health Division (1) during the 1990s and early 2000s were selected on the basis of their close relation with the creation of ANUSSAM.

Users were harder to reach, revealing an asymmetry between the visibility of their accounts and those of policy agents. Activist users have fluctuating trajectories, with periods of heightened activity followed by relative absence due to changes in their lives. The two main originators and ongoing leaders of ANUSSAM were interviewed as were three users involved in advocacy at that time. Three family activists were also interviewed. All interviewees continue to be active in the mental health field, within academia, policy or advocacy, so their perspectives are inevitably grounded in the contemporary challenges of the field, including the challenge of involvement itself.

### Interviews

Interviews were conducted in Spanish, and audio-recorded. They lasted between 45 and 120 minutes. Current policy makers were interviewed in their own work environments. Former policy makers held academic positions and were interviewed in universities. Family activists were spread

across public health institutions and NGOs. Since ANUSSAM has no formal space or office, activists were interviewed in their houses, workplaces or public places such as coffee shops.

Interviews followed each participant's early involvement in the field, their views on user involvement during the 1990s and 2000s, the creation of ANUSSAM and the context of its emergence, its development as an organisation and its interaction with the mental health system. The interviews also covered participants' views on the current challenges faced by user organisations, and by the mental health system as a whole.

*Context-setting documents*

To trace policy processes, 56 documents were selected from the Mental Health Department and the Library of the Ministry of Health. They include National Plans, Local Mental Health Plans, Clinical Guidelines and Protocols, Evaluation reports and Legal Documents. They were used to verify facts and milestones reported in the interviews. ANUSSAM provided all of their written information, 26 documents, including funding proposals, reports of activities, and administrative and legal documents related to their legal consolidation.

*Ethics*

The research process was conducted in full accordance with the LSE's Research Ethics Policy and Procedure, and formal ethical approval was granted. Since users were approached through their own organisation, not by virtue of their engagement with health services, ethical approval from a health service IRB was not required.

Interviewees took part under conditions of voluntary informed consent. The nature and aims of the research project were clearly explained both over email and in person to the participants. Participants were given the option of having their interview anonymised. For the sake of consistency and to reduce possibilities of identification, pseudonyms are used in this paper.

*Analysis*

Thematic analysis was applied by the first author to the interview transcripts, with a coding framework combining deductive and inductive themes.  The analysis focused on how users, their roles in policy, and the

notion of user involvement were understood at different points in time. At this stage, themes describing the nature of user involvement, such as 'early organizing practices', 'notions of advocacy' and 'representativeness' were identified. Relations between the themes, their changes over time, and their relations to contextual elements were also explored in order to produce a historicised understanding. Written sources helped to cross-check and contextualise emerging interpretations.

The understandings of user involvement that emerged in the thematic analysis were not uniform across time. A second stage of analysis clustered the meanings of user involvement that were dominant at different points. Drawing on Luhmann's (2012) formulation of sociology as the observation of how things are observed (or second order observation), this stage distinguished a series of five interlocking institutional processes in which users' agency was observed differently by policy at different stages. The presentation of the analysis follows the temporality of the oral histories, both enriching and departing from the official account of events and milestones usually presented in policy discourses on mental health policy modernisation, across the period from the early 1990s to the mid-2000s.

## Findings

Processes and events look notably consistent across the descriptions of current and former policy-makers, resembling a logical unfolding of scenarios and decisions. Regardless of the variations in how events are described or valued, a consistent distinction between the past, present and the future organises their narrative description, matching what is described in policy documents and statements. Even the doubts and self-criticism apparent in the interviews were always accommodated within narratives of progress. However, as indicated in the findings, the position of user organisations vis-à-vis the modernisation of the system reveals the contingency of that history and the shadows of this progress.

Hence, the findings are not presented as a single temporal narrative wherein the moment of emergence of user organisations can be pinpointed. Instead, five overlapping and interdependent processes are sketched, revealing an eventful, open-ended and contingent temporality. These processes directly framed the meaning of users' self-advocacy and its organisational emergence. A single timeline of macro-events is presented first (Figure 1), to guide the reader through the events, reforms and policies that marked this period.
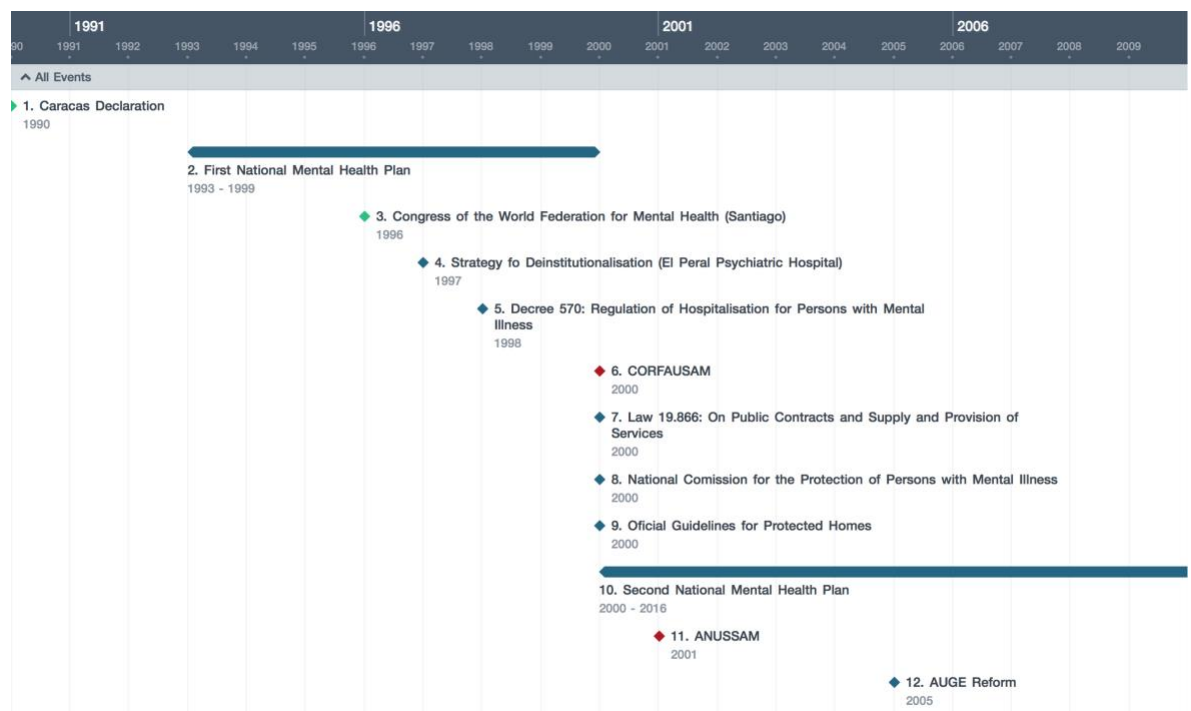
(Figure 1, a timeline of events in the modernisation of the Chilean mental health system, 1990-2005)

*First process: The Second Mental Health Plan and the need for expanded political support.*

In the overarching horizon of deinstitutionalization that defined the long term policy agenda in Chile during the 1990s, the relevance and role of family caregivers and their organisations changed fundamentally. Families became a valuable sanitary resource, at first individually, as care-providers to their family members, then collectively, as managers of protected homes in the community, and eventually politically, demanding more resources for mental health in the community. Family organisations thus gained a new status as agents in the mental health system.

According to the authorities interviewed, at the end of the 1990s, it became increasingly clear that stronger political support was required to increase the national budget for mental health and make the changes devised in the Caracas Declaration. Deinstitutionalisation was stagnated, community-based alternatives were underdeveloped and funding amounted to 1.5% of the health budget, a 0.5% increase since 1990. The main challenge was to increase the relevance of mental health in relation to other priorities. This was the goal of the Second Mental Health Plan.

In this context, family organisations became framed as an advocacy resource. Slowly, within them, users started to gain some space. Starting in

1997, and over the following three years, the MHD built up connections with them. Javiera Reyes, the executive secretary for the plan's creation, explains the rationale for involving families and users.

> We wanted them to understand the need for their participation in advocacy, their incorporation, we wanted them to give force to this national plan so it could become true. I mean, together, to push harder so this could come true. **You have to understand that at that time we were asking for some major funding for mental health. So it was important to become partners with these organisations**, recognising their contribution based on their experience. [Our emphasis]

But for authorities, who were supposed to be co-ordinating a *national* process of developing the mental health plan, selectivity became a problem, as it was unclear which user or family organisations they should engage with, which ones would add legitimacy to the plan. According to Nicolás Galiani, a key figure in the modernisation of the system who worked in the MHD during the 90s and 2000s, at that point

> (…) there were some organisations working inside or alongside hospitals, psychiatric hospitals. They were working since the 80s, there was a degree of local organisation, but I don't think they had a national organisation, I think they didn't, I think that **only when our team** [the MHD] **started to invite carers and small groups to these national events, only after that they became nationally organised, they developed a national representation** [CORFAUSAM]. [Our emphasis]

Retrospectively Nicolás Galiani observes that the representation of families at a national level was the result of an institutional effort to reach their voices and harness their support. In contrast, for Samuel Robles, original leader of the family organisation CORFAUSAM, the idea of creating a national body representing the voices and concerns of families resulted from a process of empowerment. Influenced by international experiences, different family groups sharing common concerns came together and decide to act together in relation to the authorities. While their descriptions map a process of organisational adaptation between the MHD and family groups, each side highlights its own agency in the ensuing process.

*Second Process: The Mental Health Department and the representativeness of CORFAUSAM.*

At the beginning of the 1990s, the role of family groups was framed as aiding deinstitutionalisation. Users were treated as passive, waiting to be relocated from 'institution' to 'community.' Gradually, between 1993 and 1996, more family organisations started to emerge following the preparation of a second national mental health plan. These organisations shared a

demand for more and better support that resonated with the MHD's ambitions in terms of funding and scaling up. Fernando Flores, former head of the MHD during that period, describes the excitement – and subsequent disappointment – that surrounded this process.

> There's no doubt that there was an explosive development of organisations between '93, '94, '95. In those years, we went from two to three organisations, completely dominated by doctors, organising Christmas activities and that sort of thing, to having 50 or more organisations, each with a proper legal personality. This was a boom. Over time, all these small organisations created a macro-organisation, CORFAUSAM, that originally was much more powerful than today. In a way this super-organisation both helped and restricted, because it created a structure, reducing the spontaneity, producing a specific dialogue that generated conflicts with the rest of the organisations.

CORFAUSAM was born in 1999 to unify the advocacy efforts of smaller local organisations. It had 'national representation', but it was quickly accused of being unrepresentative. Lidia Hernández, a nurse who had worked in the mental health division since 2003, links the operation of the MHD with these problems.

> (…) maybe it was the lack of funding, the lack of a different structure, I don't know, but **we had a much stronger relation with national-level representations**, because of resources. But we noticed that these national representations didn't represent the local groups. Or maybe they represented them, maybe 'representation' is not the word but what we saw was a lack of coordination between them, a lack of communication. [Our emphasis]

Limited resources forced the MHD to work with one macro-organization, despite the awareness of its lack of representation, coordination and communication with other organisations. Representation became secondary after 'the representative' is formally and irreversibly constituted. This is confirmed by Lidia:

> Let's see, I can talk about 2005-2006… that was the last year in which we [at the MHD] had an important number of registered organisations. I don't remember exactly but they were more than 100, with name, address, and membership. We did that [kept a register of organisations] only until then. After that, in a way, **we have rested on the assumption** that CORFAUSAM has that information, that CORFAUSAM unifies, that CORFAUSAM mediates, etc. Do you see? So, we've been devolving too many responsibilities on CORFAUSAM, but without working too much with them, **just assuming that they know**. [Our emphasis]

In a burgeoning and diverse world of locally organised family groups, *one* organisation had to be selected in order to reduce the complexity of engagement. More than an attribute of the representative based on its

commonalities or similarities with other organisations, representation was the outcome of a pragmatic act of selection by the mental health system. Thus CORFAUSAM was given the role of representative, even in the face of its acknowledged failures of coordination and communication with those it was expected to 'represent'.


*Third Process: The National Commission for the Protection of Persons with Mental Illnesses (NCP) and decisions on coercive measures*

One of the thorniest aspects of deinstitutionalisation was the regulation of coercive measures, particularly forced hospitalisations. In 1998, decree 570 was implemented, 'to regulate the forced hospitalisation of people with mental health problems and the services that provide it'. This decree explicitly required decisions upon forced hospitalisation to be approved by a panel of representatives of legal and scientific bodies, and also of users and family organisations. The panel was termed the NCP. The requirement of user representation led to the creation of ANUSSAM.

> The NCP, of which I'm a member right now, has one or two representatives from users' groups and that's their channel, and that helps and limits. Users' groups understand I think, that this is their only way to exchange and participate, and nothing else. (Fernando Flores)

Users became visible by the legitimacy they could add to a complex decision-making process. A specific role was required and formalised, and only then an invitation was extended. And, as Fernando Flores comments, this became the main, if not the only channel for users to express their views. At the same time, participating in a legally endowed group able to make decisions on coercion enriched and gave added justification to the notion of users' involvement, where previously only families had been addressed. This space for the first time differentiated the position of 'the user', assumed the existence of a 'user perspective', and allowed users to make a difference. According to Javiera Reyes:

> I would say that the only moment in which users had a real voice, such as Valeria, was in the National Commission. She was the only one that was able to show differences with the rest, to demand things. Family representatives did not.


*Fourth process: ANUSSAM, and a point of view emerges and evolve.*

The need for wider political support pushed the MHD to work with family organisations and, indirectly, with users. But the need to regulate

decisions upon coercion differentiated, for the first time, the voice and the contribution of users. By the late 1990s Valeria Canales was a member of CORFAUSAM and from there she became the first user in the NCP. In trying to explain what happened then – and still happens – she commented:

> A thing that users have against them is the fact that people with mental disability, according to the traditional concept, can't be healed, there's no cure. They are a problem so, 'what do we do with mental disability?' That is the big question that medicine, and society in general, obsess about: 'what should **we** do?'. [Our emphasis]

Valeria was aware of something of which policy makers and other interviewees were not. Users had been framed strictly as a problem and, until that point, for authorities, professionals and families alike, they were visible only through that distinction.

> (…) there was no participation, no users' organisations at that time, and it wasn't clear if users' organisations could live peacefully with family organisations. It wasn't easy because we needed identity, autonomy and empowerment. Families were more… protective or paternalistic, reproducing the dependencies and subordinations. For me, that wasn't a proper environment for the development of users' organisations with their own identity and autonomy.

With this in mind, Valeria proposed the idea of a user organisation to the authorities in the MHD. Among users, she approached sociology professor Gonzalo Poblete who became the leader of ANUSSAM since its birth in 2000. Their relationship with family groups was among the first challenges.

> Initially, we wanted to form an organisation together with family groups. They came to the first meetings, we had the user and the relative, father or mother, and they didn't allow the user to talk. After that, we knew we had to do this independently because re-adaptation to the family of origin is a component in the users' mental health treatment. At the end, if the relative is there, only his voice is heard, not the voice of users.

Autonomy could only be cultivated on the margins of family, both at an individual level and at an organisational level. And the same principle applied to mental health services.

> (…) in the first assemblies, we were able to bring 80, even 90 users, big numbers. But… when we started to learn and discuss more critically about services, this growth started to decay (…) families started to ask 'why do you need to go to these meetings?' Users came, encouraged by services, but only as long as we had a positive view of services.

ANUSSAM was not born as a small scale initiative, growing into a national organisation through collective action, as observed in the UK, the USA and Canada. The organisation was supposed to be big and strong from the beginning, a legally preconfigured entity with a specific internal organisation so that it could accomplish the function that the NCP and the MHD required. In the words of Gonzalo:

> We are a corporation, and this is very demanding. According to our legal statutes, we can create schools, even health services, it's a very powerful figure. (…) But we've never had that because we have no resources. We don't even have our own place to meet.

It is hard to understand how the organisation has managed to remain active over the years. They use the channels provided by the MHD, and over time other state agents have come to endorse their views and the relevance of 'the user perspective', particularly SENADIS, the national disability service. But even when talking about how exhausting and unrewarding their roles can be, the leaders express a parallel sense of achievement, mainly illustrated by moments of recognition, invitations to high-level meetings and participation as experts in policy processes, including the NCP, and the UN Committee on the Rights of Persons with Disabilities. They were the vanguard, becoming the first users in places dominated by medical and administrative authority.

*Fifth Process: AUGE*

In 2005, four years after the creation of ANUSSAM, a new reform process became national law: the AUGE reform. Its aim was to expand access to health to all Chilean citizens suffering from one or a combination of diseases included on a priority list. Diseases were selected on the basis of four criteria: the burden of disease; effectiveness of treatment; capacity of the health system and costs. The AUGE reform brought fresh funding for the still ongoing deinstitutionalisation process, and, over its three first years, the MHD managed to include three mental health conditions (Schizophrenia, Depression and Drugs and Alcohol Abuse), but at a price. Talking about the effect of this reform, Fernando Flores:

> Yes, clearly, I would say indirect, unnoticed, unpremeditated. But certainly, when we got schizophrenia into the AUGE, it was impossible to include something for the caregiver within that package, something for self-help groups or for protected homes. Then, by exclusion, this weakened the social participation of carers and groups.

The selection of diseases had to be accompanied by a rigorous and narrowly biomedical definition of a treatment, in the form of a 'package'. Services of all kinds became rigorously quantified, for this was the only way to introduce fairness and control in the administration of health resources. This had further consequences:

> The reform demanded documents and guides. A guide wasn't only for the public system; it was also for the private. Therefore, we were instructed to work only with evidence, so evidence reviews became more important. We had to work primarily with scientific societies and users were left behind. The health ministry didn't include users, and we had so many goals to achieve that users were left behind. The same with money, we had to fight every penny from the head of finances in the Ministry, he looked at our packages asking 'what is this? a community activity?' I mean, they opposed everything related to community-based activities, it was a technocratic nightmare. (Nicolás Galiani)

'Evidence' became the main criterion not only for the definition of treatments but, indirectly, for the selection of voices authorised to make that definition. According to Lidia Hernández, who experienced this process from the beginning:

> Somehow we are commanded to base everything we say on evidence. Since our role is to make policy, programmes, protocols, norms, guidelines… everything has to be universal. So you look for evidence that says, for example, how important is social participation in the treatment of schizophrenia. You write the terms and make a search, and nothing, there's nothing.

As well as changing the ecology of 'stakeholders', AUGE introduced an added organisational dimension that further affected the relation with users. According to Lidia Hernández:

> So, from 2005 onwards, with the sectoral reform [AUGE] came the division of functions. We [the MHD] remained in the Public Health Division, the area where policies, norms and protocols are elaborated. Our budget was also split, and all the funding remained in the hands of the other division, in charge of implementation. Our budget was reduced, our administrative possibilities to work more directly and systematically with users are very limited. All we did up until that moment was stopped.

According to all the participants, since the mid-2000s, there have been no major transformations or improvements in the formal relation between the mental health system and users' organisations. The last survey of organisations operating in the country was conducted in 2005. After that, the role of interaction with the universe of users was assumed by CORFAUSAM, an organisation that has been explicitly questioned by authorities and users alike.

The Second National Mental Health Plan of 2000 has not been replaced by a new Plan, after more than 15 years. Chile does not have a Mental Health Law, deinstitutionalisation is stalled and funding remains below PAHO's standard. In this sense, the fragility of ANUSSAM matches the patchy modernisation of the sector and its diminished position in the wider context of the health system.

## Discussion

> Direct initiatives by users could have emerged but users have not had the ability to develop a powerful claim, or to develop a self-help movement, or for advocacy, or to multiply organisations… there's no activist organisation across users, no activism to create new organisations, there's no power, no empowerment to engage with the legislators and authorities. And there's no working methodology within them – (Nicolas Galiani).

Interestingly, this quote matches what is expressed in the latest WHO Assessment Instrument for Mental Health Systems: 'a low presence and a poor level of organisation of the mental health users and family members' associations is still observed' (World Health Organization & Ministerio de Salud, 2014, p.11). This is the representation that currently circulates as fact at a national and global scale.

However, when the position and value of user organisations is placed in the context of larger institutional changes in the mental health system, a different image emerges. According to this reconstruction, and in line with critical approaches in the field (Brosnan, 2012; Carr, 2007; Lewis, 2014; Pilgrim, 2005), the visibility and organisational potential of users has historically responded to specific policy scenarios and institutional requirements external to users themselves, scenarios configuring specific forms of representation and relevance.

Our reconstruction shows that, for the prospect of deinstitutionalisation, families became a key resource and ally, initiating a process of organisation, guided by a real need for support and information. Eventually, one organisation, CORFAUSAM, assumed the role of representative, engaging directly with the MHD. It was the need for expanded political support for the second mental health plan which created the impetus for formal, national-level family representation. The agency was not one-sided; these processes opened possibilities of reciprocal adaptation, guided by a horizon of action that went beyond each side's interests: deinstitutionalisation. More importantly for the aims of this paper, the sequence of policy scenarios

created a dual framing for the observation of organisations working outside the clinical realm: As collaborators, articulated with the system's plans and actions and, at the same time, as carriers of true advocacy and representation. This dual framing conditioned the way in which user organisations would eventually be configured and approached.

The need to legitimise decisions about coercion differentiated, for the first time, users from family representatives. Only at the interface between the medical and legal systems did users acquire visibility, not just as supporters of the MHD's request for funding and relevance, but as users, with an irreplaceable perspective on the damage and consequences of coercive measures. Users on the NCP would be claiming to 'represent' users, and ANUSSAM was created as a national organisation to allow that claim. Again, it would be a mistake to frame this process as simple utilisation or co-option. The legal side effects of deinstitutionalisation gave users a role in deciding what could be done against the will of other users. Thus users were constituted as independent stakeholders.

However, the channel opened by the NCP became the only formalised space for users to be heard. Any potential growth in this relation was blocked by the AUGE reform of 2004. AUGE, with its imperative of equity in the distribution of services, transformed the way in which diseases were conceived and treatments designed and, as a side effect, the way users and their experiences were valued and dealt with by the system. Since the plan meant secure funding, political support from users was no longer needed and the clinical distinction prevailed, framing users, again, as a problem, and not as a stakeholder with a specific contribution to make. If users were engaged at all, they were approached through the representation of CORFAUSAM and ANUSSAM, whose authenticity was questioned, both by authorities and by users, because of their proximity to the MHD.

In this sense, in the context of a fragmented mental health system struggling for its own stability, the legitimation that users can add only makes a difference in relation to certain decision-making scenarios. The value of 'experience' is differently constituted or *commodified* (Renedo, Komporozos-Athanasiou, & Marston, 2017) in the context of evidence-based policy reforms (as in the AUGE process) than in the context of medico-legal procedures to decide on the administration of forced treatment. While in the first context statistical evidence of treatments carries more weight than user experiences for the definition and communication of protocols, decisions upon coercion carry an irreducible controversy that cannot be closed through evidence and protocols, actualising a demand for legitimacy that gives value to users' experiences and claims.

In our reconstruction both scenarios are simultaneous, they are both aspects of the modernisation of the mental health system, understood, following Luhmann, as increased differentiation across internal domains (Castel, 1975; Luhmann, 2013). This is accompanied by a differentiation in the observation and the relevance afforded to users and their organised activities. In this sense, a critique of definitions and initiatives of participation within mental health systems needs to be matched by a recognition of the internal complexity of this field and its process of historical stabilization within the health system and other relevant contexts such as the legal system. This dual attention makes possible the 'second order observation' of how users are observed.

## Conclusions

*Historicising involvement*

The declaration of user organisations' low presence and fragmentation in Chile, as in many other countries, should not be seen as 'inaccurate' in a purely referential sense. As a snapshot of the current level of organisation and the strength of users' influence in policy, the assessment is not substantially different from what users themselves say about their current capacity to organise and mobilise others. But, in the words of Gadamer, 'we miss the whole truth of the phenomenon—when we take its immediate appearance as the whole truth' (Gadamer, 2004, p.300). Only through the inclusion of time is possible to see the snapshot itself as the result of contingent institutional drifts shaping the visibility of users.

For this reason, we suggest a historicisation of users' involvement as a meaningful category in the mental health field. Tracing the concrete processes underlying how the meaning and value of involvement has shifted gives contextual substance to the notion of participation (Campbell & Burgess, 2012) against a purely technical or clinical justification. In this sense, involvement cannot be prescribed or simply 'implemented' as an item in a context-indifferent formula for a modern mental health system, as framed in the Global Mental Health Action Plan and other international calls (Saxena & Setoya, 2014; World Health Organization, 2013). Instead, these calls and their local uptake constitute an opportunity for a more substantial discussion about the contexts, meanings and practical expressions of involvement.

Moreover, recognising the temporal dimension of involvement opens analytic alternatives to a normative critique of 'failures' of participation

common in the literature (Barnes, 1999; Brosnan, 2012; Lewis, 2014; Pilgrim, 2005). Instead of evaluating involvement within a fixed normative grid, which Contandriopoulos calls the classical approach to public involvement in health (Contandriopoulos, 2004), our reconstruction points to an assemblage of policy requirements and instances of self-identification (Voronka, 2017), multiplying sites of agency and shaping the subsequent parameters of visibility. While authorities ascribe agency and responsibility to themselves, users and families also created opportunities, while all groups were subject to deep transformations in the mental health system and its relation to other powerful systemic forces, as a sociosystemic framework can elucidate.

*A systemic view on mental health and users' involvement.*

Across our history, processes of selection and need for legitimation explain why and how users became relevant as a group on the basis of the mental health system's changing requirements (El Enany et al., 2013; Harrison et al., 1997). A systemic approach radicalises and enriches this insight by framing the mental health system as a social system, and users as shifting in and out of the system's scope of visibility or relevant environment. For the mental health system, the actions of users have to be dealt with selectively, in the context of multiple simultaneous requirements and pressures coming from other systems (the legal system, the political system and, particularly, the broader health system). The dominant framework for the selection of users' communications and actions is the clinical distinction between health and illness. This is the distinction that justifies the very existence of the mental health system, and, as such, guides the way in which the system observes its outside, allocating relevance or irrelevance to specific 'irritations' (Luhmann, 1989). In this context, the involvement of organised users and the recognition of their forms of self-advocacy constitutes a double improbability: The fundamental improbability, for users, of being observed and recognised outside the guiding distinctions of the system, and, if this happens, the improbability of their views matching the selectivity of the system, and being incorporated into its own operations.

On the other hand, a systemic framework places the emphasis on contingency rather than on any particular *telos* towards which institutions or civil society agents move (Mascareño, 2006). Post-dictatorship mental health policy can be seen as a fragile, meandering realm in permanent search of stabilisation, jumping onto opportunities of relevance and experimenting with its own identity (Pors, 2012). In analytical terms, and against a tendency to locate power and control exclusively in the hands of the mental health system, a systemic perspective invites us to see the shifts in mental health

policy as responses and strategic adaptations to an ecology of systems which compete for resources and establish the terms of legitimacy of different actors. In other words, the notion of authenticity needs to be studied as a communicative tool within contingent policy scenarios, and not simply assumed as a parameter of evaluation of the action of users and other groups outside the mental health system.

Two further challenges stem from this perspective. First, a challenge to explore the analytical potential and limitations of systems theory for the observation of policy as a contingent realm where groups in society are produced and observed. And second, more politically, a challenge to historicise involvement and reconstruct its contingent basis as the grounds for the strategic irritation and transformation of mental health systems.

## Notes

(1) In 2005 the Health System was divided into a Public Health Division, in charge of the design and implementation of policy, and a Care Network Division, in charge of the concrete operation of healthcare. Originally working for the Mental Health Department, the participants were then divided into two departments, one in each division.

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Title: **'Making contact'. Tentative engagements between institutions and communities in Chile's mental health field**

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## Abstract

In Chile, since the early '90s, service-user involvement and community participation have featured prominently in policy discourse, but with no formal and explicit guidelines, plans or associated funding. Without formal models, and based on fragile administrative and financial grounds, local health services have tried to develop small-scale mechanisms of involvement.

Taking one such attempt as a case study, the aim of this paper is to explore the process by which, in contexts of informality and facing unfavourable institutional conditions, mental health services attempt to 'make contact' with community-based groups including service-user initiatives. We interviewed policy makers (5), professionals (10), service users and other community agents (5) linked to a concrete participatory initiative in the south-east area of Santiago. Participant observation and prior knowledge of the service and the area helped to contextualise and enrich the interpretations.

The findings are structured as a temporal sequence of decisions and adjustments made to the initiative. In an initial move, a health service developed a network of local groups. To populate and rationalise the new network, funding was offered to local groups, and made conditional on specific formalities and the presentation of projects. A regime of meetings between local agents and professionals was established, but new problems emerged, related to the diversity of the groups, the distribution of leadership within them, the general coordination and shaping of the network, and the selection of projects to be funded. Each problem emerged as a result of prior solutions, mobilising bureaucratic adaptations and demanded a sense of unity and coherence among the groups composing the network.

Despite the growing attention paid to participatory policies, the way in which institutions initially approach and conceptualise their exteriority and the administrative complexity involved in this process has received scant attention. By approaching participation as a time-based, tentative

phenomenon, a series of aspects defining the concrete life of participatory projects becomes visible, including a permanent and growing professional anxiety regarding the potential de-legitimation of their roles and decisions, and the resulting drive for control, expressed through the production of different and contradictory conditions for the participation of user groups.

On the basis of these findings, we claim that informality should not only be viewed as deficiency or incompleteness. The tentative and disoriented steps taken by bureaucracies to approach communities are informative of how participatory logics and practices emerge and evolve at the local level and how broader policy factors and professional values come to play a role in the process. Calls for service-user involvement therefore need to consider the local dynamics involved in the production of engagement between health services and local groups.

## Introduction

Over the last few decades, calls for service-user involvement in mental health policy have gained prominence across countries and regions. Originally demanded by users themselves, the idea of involvement is increasingly framed as a basic aspect in the definition of an adequate mental health system worldwide (World Health Organization [WHO], 2013).

Beyond cursory mentions in policy documents since the 1990s (Ministerio de Salud, 1993, 2011), in Chile there are no formal mechanisms or guidelines around service-user involvement in mental health services. Funding for mental health is below WHO standards, representing 2.15% of the total health budget (WHO & Ministerio de Salud, 2014), and while recent reforms have secured the availability of services for specific conditions (Errázuriz, Valdés, Vöhringer, & Calvo, 2015), community-oriented interventions are excluded from this selection. Unsurprisingly, a recent assessment of the mental health system has identified a 'low presence and insufficient degree of organisation of service-user and family groups' (WHO & Ministerio de Salud, 2014, p. 25).

In another paper, we have linked the irrelevance of service-user organisations to a series of recent policy transformations within and beyond the mental health field (Montenegro & Cornish, 2017). In the present paper, we want to pay closer attention to how, in the absence of formal guidelines and facing precarious financial and administrative conditions, local services conceive and create forms of work with local groups and communities at large. We address these questions through a case study of the Community Mental Health Network, a concrete participatory initiative developed in a

public health service, in one of the poorest and most populated areas of Santiago. It is based on 22 semi-structured interviews with a range of agents linked to this initiative. Transcribed interviews were thematically analysed and the interpretations were also informed by field notes based on participation in seven meetings linked to the initiative.

Many studies about participatory initiatives in mental health are based on formal projects with clear boundaries in time and space, usually including documentation about goals, responsibilities, indicators, etc. (Everett, 2000; Rutter, Manley, Weaver, Crawford, & Fulop, 2004; Tremblay, Coulombe, & Briand, 2017). Such initiatives are approached with an evaluative or critical aim, identifying the gap between design and implementation (Kleintjes, Lund, Swartz, Flisher, & The MHaPP Research Programme Consor, 2010; Tambuyzer & Van Audenhove, 2013) and/or revealing the underlying - and undermining - political, economic or ideological drives behind participatory agendas (Beresford, 2010; Harrison, Barnes, & Mort, 1997; Pilgrim, 2005). Yet, little attention has being given to ways in which institutions initially approach and conceptualise their exteriority and the administrative complexity involved in the process of making contact.

The fragility and informality of participatory initiatives in Chile's mental health field offers a relevant scenario were to trace the tentative steps taken by health organisations to contact communities and the values and ideas that guide this process. The following section briefly introduces the main aspects of mental health policy in the country and the status of participation and community-oriented work within this field.

*Health reforms and legacies of participation in Chile.*

Community participation as a principle of public health development in Latin America can be traced back to international and regional processes in the 1970s and 1980s. This section discusses three main antecedents: The Alma Ata declaration, the 'Community Mental Health Policy' after deinstitutionalisation and the complex effects of recent health reforms upon the reality and possibility of participation. Finally, the specific initiative serving as a case study for this article is presented.

*Alma Ata*

In most of Latin America, the main drive for community participation in national health programmes took place in the seventies, thanks to the influence of PAHO and other international agencies such as UNICEF

(Ugalde, 1985). The Alma Ata Primary Health Care Conference of 1978 and its ensuing declaration redefined the responsibility of States in providing adequate health services for all in a spirit of social justice, stressing the importance of primary health care and framing community participation as a fundamental prerequisite for effective health care (WHO, 1978). For some commentators, since 1990 'Chile has progressively implemented a primary-health-care approach focused on the community' (Jong-wook, 2003, p. 2087). Has this been the case for mental health?

*From asylum to community*

For most of Chilean history, the asylum constituted the dominant institutional response to the 'mad' (Minoletti, Rojas, & Sepúlveda, 2010). In the wake of deinstitutionalisation in Europe and North America, a series of alternatives were explored by pioneering psychiatrists, following Franco Basaglia's process in Trieste and the 'Movement of Community Psychiatry' in the USA (Maass, Mella, & Risco, 2010; Scheper-Hughes & Lovell, 1986).

Dictatorship shut down these incipient community-based experiments (Mendive, 2004) and, between 1973 and 1989, mental health services were reduced to psychiatric hospitalisation (Sepúlveda et al., 2012). In 1980, the military 'junta' enforced a new constitution that opened the health sector to market forces, while maintaining a chronically underfunded public sector for the poor. By the end of dictatorship, the health budget was concentrated in four understaffed and overcrowded psychiatric hospitals, amounting to 1% of the total health budget (Minoletti et al., 2010).

In 1990, the 'Conference for the Restructuring of Psychiatric Care in Latin America' was celebrated in Caracas, and the ensuing Caracas Declaration was signed by all ministers of health of the Americas (Bolis, 2002). The Declaration called for a series of transformations, including the reduction of funding towards closed psychiatric hospitals and the creation of community-based alternatives, the need to integrate mental health services in regular health settings - especially primary care - and the development of legal safeguards for the respect of the human rights of patients (Saraceno, 2007). These principles served as a foundation for the first and second National Mental Health Plans in Chile (Minoletti & Zaccaria, 2005).

Although the implementation of these principles has been slow and uneven, studies have demonstrated a sustained shift towards the development of ambulatory mental health services, universal availability of mental health services in primary care settings, and other indicators of progress devised in Caracas (Minoletti, Galea, & Susser, 2012).

Simultaneously, the plans, consolidated the 'community model of mental health', a lasting framework and a transcendent aspiration of mental health policy development in the country (Minoletti, 2016).

*New reforms*

At the end of the century, an ambitious health reform called 'Universal Access with Explicit Guarantees' (AUGE according to its Spanish initials) was developed. Becoming effective in 2005, its aim was to expand access to health care to all Chilean citizens suffering from a number of diseases included on a priority list (Dannreuther & Gideon, 2008). Three mental health problems were covered, bringing new funding to the mental health sub-field (Errázuriz et al., 2015; Montenegro & Cornish, 2017).

This reform organised the provision of health care around individualised diagnosis associated with specific amounts of funding (Encina, 2014). Community-oriented activities are not recognised as fundable health interventions. The latest National Mental Health Plan (2017) acknowledges that a consequence of this shift is the 'dissonance between the administrative ideals of the community mental health model and the demands of a model mostly based on the fulfilment of quantitative goals (…) This distracts the attention of the local authorities, displaces the actions of promotion and prevention *and limits the effective participation of the community in local health actions*' (Ministerio de Salud, 2017, p. 2).

Each mental health plan in the country has insisted on the community model of mental health. The notion of community has evolved from being synonymous with ambulatory mental health services to becoming a normative principle, guiding every action of the mental health system. However, the economic rationality of the system is based on strict biomedical definitions of disease, prevalence and treatment costs. This contradiction sets the scene for the development of local participatory initiatives.

*Case-study setting*

The Community Mental Health Network (CMHN) is an initiative developed by a team of professionals working in the mental health department of a health service in the Santiago Metropolitan Region. A health service (HS) is the name for the office in charge of the administration of the network of public health providers of a specific territory, including hospitals, primary care services, community mental health services, etc. The territory

under the administration of this HS comprises seven 'communes', the smallest geographic subdivision in Chile. Of 29 HS in the country, this serves the largest population, and includes some of the poorest areas of the metropolitan region (Agostini, Hojman, Román, & Valenzuela, 2016).

According to the interviews and the documents collected by the first author, in 2005 a local mental health team developed a small and active network of self-help groups linked to problems of alcoholism, operating in a deprived area of Santiago. In 2010, the HS decided to use this localised experience as the basis for its own platform of engagement with community-based groups across its territory, including different local organisations whose work fell within the remit of wellbeing and community development. This was, according to the interviews, the beginning of the CMHN in its current shape.

This paper examines the context in which this initiative emerged, the tentative schemes of interaction and collaboration produced and the policy principles and ideas that guided the process, to understand how participation is translated into concrete strategies, roles and actions, in the context of adverse institutional conditions.

*Participation as an object of social enquiry*

Participation in health systems is notoriously polysemic (Stewart, 2016). It not only includes many different practices, but encompasses contradictory goals within institutions (Martin, Carter, & Dent, 2018). It covers notions such as involvement, consultation, public engagement and, more recently, co-production (Wait & Nolte, 2006). As noted by Stewart (2016) this semantic instability is matched by a general lack of interest in conceptual development in the field.

Among the literature on service-user involvement that comes from the social sciences, two broad lines can be analytically distinguished. On the one hand, an evaluative approach interested in assessing participatory initiatives in relation to their impact upon health or other relevant dimensions (Kleintjes et al., 2010; Omeni, Barnes, MacDonald, Crawford, & Rose, 2014). Another critical focus examines how such initiatives serve underlying agendas linked with broader social and economic transformations (Pilgrim, 2005; Tomes, 2006) including a generalised move towards a consumerist culture in health policy (Milewa, Valentine, & Calnan, 1999; Tovey, Atkin, & Milewa, 2001). Some researchers explicitly draw on their own experiences at the receiving end of services to further sustain and expand these critical

approaches (McWade, 2016; D. Rose, 2003; D. Rose, Carr, & Beresford, 2018).

Most of these studies are based on formalised participatory policies or projects within clear temporal and/or spatial boundaries. They try to capture the way formal participatory initiatives are understood and experienced by the agents involved in them, and they usually focus on the dissonance between policy ambitions and concrete implementations. Still, as seen in the prior section, this cannot be assumed in the Chilean case, where there are no formal participatory mechanisms targeted to users in mental health services, but where, simultaneously, notions of community and participation have pervaded policy discourses for decades. Scenarios of informality and experimentation do not lend themselves immediately to either an evaluative or a critical approach. How can they be accounted for? In what sense they matter?

According to Damien Contandriopoulos (2004), most approaches to participation in health policy are based on normative ideas about what participation should be, linked to notions of democracy, transparency and empowerment. This produces a tendency to focus on the deficiencies rather than on the concrete characteristics of participatory projects. Furthermore, such perspectives take '(…) an implicit standpoint regarding the intrinsic desirability of public participation' (2004, p. 321). He proposes an approach that attends to the ways in which the agents involved in participatory health projects engage in a struggle to 'influence each other's perceptions of their respective positions and, more generally, their perceptions of the reality as a whole' (2004, p. 322), including the reality of participation itself. In a similar way, Cefai et al. (2012) calls for an approach to participation that assumes its initial indetermination, the fact that it cannot be simply deduced from a normative ideal but that it is assembled differently in a different context, in ways that only direct engagement can reveal. In his words, 'the whole point of an ethnography of participation is then to study it as it is, and not as it should be' (2012, p. 8).

Based on ethnographic work on participatory development projects in India, David Mosse defends an approach to policy projects that goes beyond an instrumental interest in their efficacy and a critical interest in their ability to conceal underlying dynamics of power and domination (2004). For him, such approaches 'divert attention away from the complexity of policy as institutional practice, from the social life of projects, organizations and professionals and the diversity of interests behind policy models and the perspectives of actors themselves' (2004, 644).

Although normative inclinations cannot be entirely suspended in the study of participation, in this paper we follow these and other authors (Glimmerveen, Ybema, & Nies, 2018; Renedo & Marston, 2015) in an attempt to understand participatory initiatives as localised practical achievements that selectively draw on broader policy orientations and local configurations of interest. Using the CMHN as a case, this paper aims to respond to the following questions: How, in contexts of informality and facing unfavourable institutional conditions, do mental health services attempt to contact community-based groups, including service-user initiatives? What role do broader policy orientations play in the emergence and sustainability of participatory initiatives?

## Methodology

### Approach

This paper is a case study based on the Community Mental Health Network (CMHN), a concrete participatory initiative in the south-east of Santiago. It draws on semi-structured interviews, participant observation and relevant documents. The interviews were conducted between July and December 2015 with a purposive sample of policy-makers, professionals and service-users linked to the initiative. This included five respondents from the Mental Health Unit of the Ministry of Health, five professionals working on the mental health team of a health service in the Santiago Metropolitan Region, five professionals working in front-line mental health facilities corresponding to that health service and five service-users working in community-based organisations belonging to the network.

The interviews were conducted in Spanish and audio-recorded. Participants were asked to describe the participatory activities that they knew or were involved in, and in the course of these descriptions they were asked to expand on their views on participation in general, the potential roles of service-users and professionals and the broader conditions limiting or allowing participatory actions and community-oriented work. The interviews lasted between 45 and 120 minutes. All professionals were interviewed in their own work places. Users were interviewed in health facilities where they developed activities (e.g. self-help groups), in other local community facilities or in public spaces. A topic guide was used that included general questions about service-user participation and more specific questions targeted to each type of respondent.

Participant observation involved seven meetings that lasted between two and three hours. The purpose and composition of these meetings varied.

Four were official meetings of the CMHN, while the other three were aimed at providing local feedback to a National Mental Health Plan draft, and CMNH user members were invited to act as user representatives. Participant observation was focused on the interaction between service-users and professionals, the issues raised by service-users and the responses and reactions of professionals.

Finally, internal administrative files documenting certain aspects of the CMHN and its funding structure were used to better contextualise the findings.

*Ethics*

The research process was conducted in full accordance with the LSE's Research Ethics Policy and Procedure, and formal ethical approval was granted. Interviewees took part under conditions of voluntary informed consent. The nature and aims of the research project were clearly explained both over email and/or phone and immediately before each interview and/or group activity. Participants were given the option of having their interviews anonymised. For the sake of consistency and to reduce possibilities of identification, pseudonyms are used across the paper, and the specific settings are also anonymised.

*Analysis*

The findings reconstruct the creation and evolution of the CMHN. They are structured as a sequence of decisions made by professionals oriented at making contact with local communities, and the consequences of these initial decisions. This temporal sequence also organises the views of the different agents about participation and community-oriented work.

The analytical process leading to this structure requires some contextualisation. Initially, the aim of this research project was to understand the perspectives of professionals and service users about service-user involvement in mental health settings. With this in mind, a topic guide was developed that included four broad themes: 1) Service-user roles in health settings; 2) Organisational conditions for involvement; 3) Institution-community interactions and 4) Professional roles in participation.

Nevertheless, during fieldwork, the existence of concrete participatory initiatives - including the CMHN - was revealed, something that was not mentioned in the available information about the health service. This was

also manifest in the interviews, with respondents using the CMHN as the main reference to talk about participation in general. Increasingly, the interviews transitioned from the originally defined topics to an interest in the origins, characteristics and problems of the CMHN and in the way different agents conceived it and approached it. The first author participated in all the relevant CMHN-linked activities available during fieldwork.

The decision to structure the findings as a temporal sequence centred on the emergence and development of the CMHN - and therefore, to make this a *case* study instead of a study of representations about participation – was in response to this unanticipated aspect of the fieldwork. Software-assisted thematic analysis was used to organise and make the contents of the interviews retrievable, but instead of a structure of a-temporal themes, the views of respondents are anchored in a sequence of concrete actions and situations (Maggetti, Gilardi, & Radaelli, 2014). Privileging the temporality of the project also enables recognition of the doubts and concerns that emerge and form part of the process, avoiding the simple repetition of fixed normative positions around participation. Participation was discussed as something that respondents were - at least partially-responsible for, and not as an abstract possibility about which they could play out different opinions.

**Findings**

*Making Contact*

In 2005, a local Community Mental Health Service (or COSAM) operating in a deprived commune of Southeast Santiago started to develop an active network of self-help groups linked to problems of alcoholism, domestic violence and depression, priority areas according to the first and second National Mental Health Plans. The COSAM was the main organisational component of the post-dictatorship mental health strategy (Ministerio de Salud, 1993) but their development was slow, with important variation among them and with different approaches to community-oriented work.

In an attempt to standardise the way services worked with local groups, and make the network of groups extensive to its seven constituent communes, in 2010 the HS decided to use this small-scale initiative as the basis for a larger platform of engagement called the Community Mental Health Network (CMHN), that could include not only self-help groups but any local group whose actions had an impact on the wellbeing of the community. According to available documents, this was a way for the HS to 'assume the

direction of the relation with the community' (internal document). For Oscar Ulloa, a psychologist that actively participated in this process:

> This transformation has two aspects. It is about centralisation in the health service, but at the same time it is a decentralisation and expansion across the territories. The original groups that started at the local level were very homogenous, closely related and close in distance. They were mostly self-help groups linked to pathologies: 80% alcohol, a bit of depression, a bit of domestic violence and that's it.

Aspects of the Second National Mental Health Plan (Ministerio de Salud, 2011), whose principles were known and discussed across mental health services in 2010, can be linked to this shift. It placed a strong emphasis on prevention and promotion and on the need to understand mental health as an intersectoral responsibility. In contrast, during the nineties, and in the context of deinstitutionalisation, local family groups assumed the work of rehabilitation and social inclusion of discharged patients, where local groups were understood, in this new vision, as agents of prevention and promotion within the community. Pathology-based self-help groups did not represent the kind of entity that could be articulated to this vision. Mental health promotion had to involve a broader set of local partners.

At the same time, the transformation and creation of the CMHN had a relevant financial dimension. As seen in the introduction, the AUGE reform meant that HS were funded on the basis of individualised diagnosis and associated treatment costs, excluding community-based activities. To support local self-help groups the 'Law 19.925 on expenditure and consumption of alcoholic beverages', or Alcohol Law, was used (Ministerio del Interior, 2004). In Chile, alcoholism has historically been a priority both from a public health and a social security perspective (Marconi, 1999). This has prompted a number of inter-sectoral policies that, among other things, financed the development of self-help groups with the stable reserves of drunk-driving fines (Ministerio de Salud, 2010).

Before 2010, these funds were directly transferred to self-help groups. According to Claudio Farías, a psychologist in charge of the administration of these funds at the central level, this had to change:

> These self-help groups were used to receiving a monthly allowance without conditions. We are trying to change this logic, implementing the idea of a 'competitive fund'. Each local group has to submit a project to participate. On the basis of the available funds, the HS decides the amounts and other conditions. (…) our idea is that these funds are used in a project that transcends the local group and its members, something

that can be expanded to the wider community, like workshops or promotional work.

This new approach to funding was a key element in setting up the CMHN. Before 2010, local self-help groups were funded on the basis of their contribution to the rehabilitation and support of persons with problematic alcohol abuse and related situations or in the care of patients discharged from psychiatric institutions. After the transformation, funding was seen as an *investment* and became conditional on the formalisation of activities and the development of a project that could make an impact *beyond* the group.

These changes, nevertheless, were also justified by the need to modify the paternalistic relationship between professionals and local self-help groups that, according to the professionals involved in the creation of the CMHN, characterised the initial setup. According to Oscar and other professionals involved in the process:

> The original groups had a much-infantilised view of their needs, they would say 'no, we are not autonomous', 'we can't do this'. And professionals participated in this, working in a very paternalistic way, basically assuming full responsibility for the groups (…). Professionals did everything for the group, they assumed the responsibility to fund the groups. They never installed any capacity in the groups. There was no vision of the future.

The initial constitution of the CMHN exemplifies a number of transformations in the way mental health services understood and approached communities. A focus on promotion above treatment broadened the scope of potential local partners and cast doubts about the suitability of traditional self-help groups. Conditionality of funding was based on the idea that groups had to make an impact beyond themselves, participating in the promotion of wellbeing within communities. It was a way to rationalise the selection of local groups, forcing them to become independent and sustainable. More broadly, 'community' passed from being an indifferent space, where self-help groups develop closed activities, to becoming the simultaneous agent and target of mental health promotion (Rose, 2000).

Eventually, invitations were distributed across local COSAM and through mental health professionals working in primary care. The groups that were already working in the original scheme were integrated and new groups were slowly added, attracted by the availability of funding. The same funds allowed the HS to create new professional roles in each commune, in charge of supporting the network, and a new regime of interaction with local groups emerged. Yet, this initial layout created unexpected problems and the need for further adjustments.

*The problem of diversity*

> This change was good, but we need more resources because right now we're using money from the Alcohol Law, and this is unfair, because there's a lot of alcoholism in the area. Men in those groups, you know, they can't work, they are really struggling and they need those resources. (Luz Jara, service user, member of the CMHN).

> Some users said 'this is the alcohol funds, this should be destined to alcohol issues'. What do you say to that? Of course! We know that it makes no sense to use these funds in such a way but this is the only source of funding for community-work. If the health ministry doesn't develop a better channel, our only option is to use these funds, as ambiguous as that is. (Miguel Lara, Occupational Therapist, HS).

The alcohol law was not meant to fund community work beyond the self-help groups. It was an improvised and fundamentally fragile funding mechanism and every interviewee agreed on this. It created tensions with its legitimate recipients, self-help alcoholism groups. However, it was the only source of funding and it gave the mental health team of the HS a tool to initiate this process of engagement with a broad array of groups. Renata Veliz, member of the CMHN and leader of a local initiative helping older people to retain cognitive abilities, accounts for the benefits of the funding and the network:

> The psychologist told me about this new network so I thought it was important to come to the monthly meetings, because maybe we could get some resources for our projects. That's why I started to participate, in 2010, to support my group. We organised ourselves, we submitted two projects and we won. We bought a projector, a printer and a notebook and we had enough to go on a trip with all the grannies and grampas.

Like Renata, many of the newly integrated local groups had previous connections and years of experience securing funds from public and private sources. Besides the perceived illegitimacy of using the Alcohol Funds to fund a broader scope of groups, a new problem emerged: the imbalance between resourceful organisations that could win the CMHN funds and other groups that, for many years, did not have to compete for funding. Karen Solis, a social worker working directly with the network, expressed her concerns:

> We made a lot of efforts to develop methodologies to work with them, but what happened was that these are very different groups. This makes it harder for us to find the conductive thread across them. You have the group of grannies suffering from depression, and they knit. They have no

experience in working with other groups, they don't even read. And you have the Mapuche organisation throwing projects like a machine, with institutional links and a clear political discourse. So you have this contrast between this super complacent organisation that appreciates anything you do for them and the other organisation that finds everything lacking. Finally we understood that the challenge was to find the common feeling, the common meaning and the common sense of why we were meeting. We need to work to understand what defines us as community, as a collective.

While the task of centralising and expanding the network was done, and the mechanism to allocate funding across its members was in place, the reality of the resulting aggregate of groups seemed to baffle the professionals charged with supporting and developing the network. Each group had its own background and its own reason to be there, mostly related with funding. Somehow this was perceived as a limitation. Miguel Lara makes the same point in a different way:

> We sat with this people [the local groups] and asked them 'what should we do here?', and they said 'we are here for the projects'. 'Ok, but what do we want to do, what is your vision, beyond the projects?'. I mean, 'what do you want?' 'Do you want to grow as groups?' But why do you want to grow? 'You want to have more voice?' 'But why do you want to have more voice?' I mean we need to aim much higher that just have power for the sake of having power, we need to build something together.

The creation of the network was not promoted or demanded by local groups. Rather, the network was a perfect example of an 'invited space' (Cornwall, 2004) set up by an institution for community agents to participate in it. Even more so, the CMHN deeply transformed a previously existing way of working with local groups; creating more conditions for them to participate, forcing them to become something different, demonstrating impact and formalising their activities. Still, accepting the new conditions was not enough; something was still missing - the meaning of the network itself as an emergent platform.

*The problem of leadership and representation*

As the initiative moved along, a new regime of interaction was stabilised, and this made other problems apparent, closely related with the problem of diversity: The problem of leadership within the groups, also expressed as a problem of representation. As Miguel put it:

> Through the meetings with the groups I see a problem of leadership…
> the lack of participation **within** the organisations. I mean, how they
> share that leadership. It is an issue because you always see the same

persons and you ask 'why doesn't that lady comes more often?', 'Nah, that's because she doesn't feel prepared, I can manage everything'. But ideally, you shouldn't be managing everything. If you work with the group in a more horizontal way then other representatives can come because, I mean, if only one person comes all the time, then how do we know that her opinion is the opinion of the group? [Our emphasis]

Before 2010, groups received funding and professional support by virtue of being self-help groups. Professionals worked *in* the groups. The distribution of leadership and representation within the groups becomes a problem only in the context of the new regime of interaction that, in turn, responds to the process of expansion and centralisation initiated in 2010. In the monthly meeting, groups had to be represented by someone and the repetition of faces and names across meetings became a negative trait, a signal of something else. Rosa Tapia, an active service-user that leads a self-help group for victims of domestic violence, acknowledges the problem:

> I have 12 active members registered in my group. There are others that don't want to participate but they don't want to be removed from the list. So when you get into this thing called participation, your presence is required. 'Can you come to this?', 'can you stay for this meeting?', lots of invitations and sometimes you don't have people ready to replace you in all of those meetings, so you repeat yourself and that's not ideal.

For her and other service-users, representativity is not simply invested upon them as a single act (Derkzen & Bock, 2009). It requires the permanent effort of being recognised as reliable, knowledgeable and connected. Accepting invitations is a key mechanism to sustain this recognition, confirm this reliability, gain knowledge and create those connections. It is, within the limited possibilities offered by the institution, the main labour involved in participation. However, carefully ticking all these boxes finally undermines their ability to distribute the role of representation in the CMHN. The new regime of contact, while aimed at fostering autonomy, places the internal operation of the groups as a critical concern for professionals, creating further boxes to be ticked.

*The problem of coordination*

A simultaneous difficulty was created by the new regime of contact. The network was too large and, as the first author was able to observe, the monthly meetings were packed with information - from the professionals to the groups - and activities aimed at figuring out what the groups had in common and what their shared identity was. In addition, the presence of many groups was still irregular. The meeting was not an adequate decision-making space. Still, many important decisions were needed, crucially about

distribution of funding for the projects. Those decisions could not be simply made by the professionals, because that could damage the legitimacy of the whole initiative. The solution was to create a smaller and legitimate decision-making 'committee'. Laura Vega, psychiatrist and head of the mental health area of the HS, commented:

> The committee is the representation of the network. Each commune is represented by a user and a professional. 'But it's going to be too big!'. Well, it has to be big because big decisions are made about the network. We want the network to feel represented by the committee, we want to legitimate this space because we still have problems. Members of the local groups come here and ask 'but, who did you ask about this?', 'the representative of your commune came', 'but, we don't have a representative', 'ok but we do this at the beginning of every year!'. And you always have the same problems.

The committee is composed of five members from community groups - elected by the totality of the network in an annual assembly - five professionals from the HS and local health units, and, to break the tie, a 'permanent user member'. Its creation is seen as an important achievement in terms of coordination and participation. The group is better able to make binding decisions, reacting more quickly to changing bureaucratic requirements and opportunities. Still, as a second layer of representation - representing the representatives of the community -, the committee's legitimacy seemed at permanent risk, as indicated by Laura. This is linked to the problem of diversity. If the network was nothing more than a collection of self-interested parties, there was no guarantee that a decision affecting the network would not be rejected. A degree of unity across the network had to be assumed for decisions to be made with a minimum of confidence. Unity was a bureaucratic condition for decisions to be made, more than a deficiency among the groups composing the network.

*The problem of selection.*

> Before 2010, the distribution of funds was very arbitrary. We opened the funds to other groups, and that created a bit of a crisis because, sure, the cake was divided in more slices and that created resentment. But that's not an issue anymore. The discussion now is 'what do we fund with this money? Do we fund the ladies that knit or the Mapuche group?'. We don't really have preferences, the point is doing community-work, so we decided, with the small group, that, from this year onwards, the funds were going to be distributed in a fixed amount for each commune, and the whole commune would present a project oriented to strengthening its own communal organization, working towards a more unified and territorially-relevant proposal. (Daniela Silva, social worker, Health Service).

Regardless of the sequence of democratic and administrative adaptations, the problem of selecting projects - and therefore, groups - to be funded could not be eliminated. The creation of the committee solved a number of issues, but the legitimacy of the decisions remained contested. A new adaptation was necessary. Instead of distributing the funds across individual projects/groups, the total amount was divided proportionally between the seven communes. The groups belonging to each commune were responsible for getting together and working collectively on a project. According to Cesar Ayala, the permanent user member and originator of this change:

> The funds needed a territorial utilisation. We know that this is not going to work at first, but it is good to acquire a sense of territoriality. This is related with the difference between the herd and the pack. In the herd, everybody does the same and they need a shepherd to protect them. In the pack, you preserve your individuality and work around shared goals. We want to behave like a pack because in the herd the shepherd feels like the owner of the group, but in the pack we all own the group.

This ambitious move, decided by the committee, was meant to radically transform the way the network operated, forcing individual groups to cooperate and develop a collective, territorially-based strategy. The decision was congruent with the professional's demand for autonomy, unity and transcendence: Groups of all sizes and orientations had to know each other and work together without the individual assistance of professionals. However, this was, simultaneously, a way for the committee - and the HS - to disburden itself from the anxieties of selection and the permanent risk of illegitimacy and contestation.

*The problem of contact*

According to the interviews, beyond this series of problems and adaptations, the CMHN managed to maintain its status as the main form of direct contact between the HS and local groups. Yet, in 2014, four years after the creation of the CMHN, a new 'movement' emerged from within the HS, with similar aims to that of the network. It was called the 'Citizen Movement for Mental Health' (CitM), an informal initiative led by a number of professionals - mostly psychiatrists - working at the tertiary level of psychiatric care within the main hospital complex of the HS, a group that until then had no connection with the CMHN. According to Laura:

> There's a new movement here, it's called the Citizens Movement, and it's led by psychiatrists with a very biomedical profile that have fallen in love with the community-model and that are working with an amazing strength now.

But other professionals, working on the same position as Laura, had a very different view. For Oscar:

Suddenly this movement starts, but I think there were other goals behind it. It was, basically, a demonstration of power. The first thing that the leaders of this movement say is 'there is no community mental health work or groups in the health service'... you see? That was their message. It was a small group of psychiatrist[s], they cherry-picked other professionals at the local level to spread the message. And right at that moment the director of the HS is replaced. And we haven't even had a moment to talk with the new director when this movement's leaders come and tells him 'there is no community mental health work here, why don't you help us organising this event to start a movement', without even talking with us, his mental health team. The director bought it and the idea that there was no community work was truth for him for a long time. But we have done a lot of work in creating a network for mental health in the territory.

The main concern for Oscar was the fact that this new movement was meant to be a response to the absence of community-oriented mental health work at the HS level. Not only this, it programmed its own event in the month of the year in which the original CMHN had held its event for the last four years. This created a strong conflict and was also resented by the community groups in the network.

The people in our groups were surprised saying 'do you mean we don't exist?'. And this event was supposed to be parallel to our traditional event, and it was called the 'community mental health event' and our people started to say 'but we've been doing this for four years, how is this the first one?'. So suddenly you had the movement of the psychiatrists on one side, and our group on the other (...) Although the event was massive, and even our groups participated, our network keeps working as usual and their movement is little more than an appendix, selectively participating in very specific things, with no visible results or plans. (Miguel Lara, Occupational Therapist, Intermediate Level).

Unlike prior challenges, professionals were divided about this unexpected development. After five years of work, the most complex threat in the process of consolidating the network did not come from the community but from within the very organisational structure of the HS. The ability of a small group of high level professionals to believe and spread the idea that there was no relation or work with communities revealed the radical fragility of contact and the little difference that it made inside the institution, beyond the small group of professionals entrusted with its development. Community could always be reframed as virgin territory, ready to be approached for the first time. In the words of Julio Soto, a member of this new movement:

Last year we had two parallel movements that appeared to be in conflict. There was the CMHN that works with self-help groups gathered around the distribution of alcohol funds. And then the Citizen Movement, that some called the 'psychiatrists' movement', in a derogatory way. We went to the CMHN's meetings to explain that that was not the case, the invitation was open to work together. But it was complex, they said 'why will they have their big event on the same themes and on the same dates as us?'. Finally we said that nobody owned community-oriented mental health, and that we needed to work together.

Community mental health was something bigger than any initiative or interest, and nobody owned it. This dismissed the sense of ownership that user groups had developed over time, and this resembles the original act of creation of the CMHN. While it was built upon a pre-existing effort, it actively dismissed it as too limited, paternalistic and passive. Similarly, this new movement dismissed whatever was before in order to emphasise the need to initiate a relationship with the community. This reveals that the unilateral attempts at making contact do not create any form of bond or relationship between institutions and community. More precisely, they do not make a difference inside institutions. They can always be irrelevant and replaced by a new attempt. In a paradoxical formulation, it is this very compulsion to approach the community for the first time that creates the biggest risk for the development of a more enduring bond between institutions and local communities. Cesar, the committee's 'permanent user-member' addressed this point:

At the institution you have an idea but that doesn't mean the ones in the street don't have an idea or a plan. There are many processes going on in the street. Psychiatrists really struggle to understand processes. They think about them as events, events like 'take this pill that I'm giving to you' or 'accept this treatment!', they see their actions as a defining and definitive event, not as part of a process. I don't know if you see the difference, but well, this big meeting was… I see it as a big fire made of paper. You can't cook anything with that. Processes have permanence across time, they are like stepping stones.

Key to Cesar's vision of 'contact' is time, adaptation, patience and respect. There is no defining event; participation cannot be inaugurated, regardless of the professional emphasis on the changes brought by their own action. Community work is an ordinary engagement with the ordinariness of community life.

## Discussion: Unpacking 'contact'

When you get to the meetings with the groups you don't really understand what's the point or the goals of the network. Some participants do have a strong vision, but it doesn't come through in the meetings. When a new member comes we don't have a clear story to tell, a sense of 'this is us, this is what we want, this is our work, this is our history'. I feel that something important is missing, a sense of unity, a shared story. (Karen Solis, Social Worker, HS)

The findings described the attempts of a local public mental health service in Chile to make contact with user groups in its territory, through the Community Mental Health Network. The initial process was aimed at centralising and opening the network, following a new vision of community as the agent and the medium of mental health promotion and wellbeing. To be part of the network -and receive funding - community groups needed to formalise themselves, demonstrating autonomy and making a transcendental impact. New funds attracted a broad set of groups, and this diversity created new challenges. A distinction emerged between the composition of the network -diverse in interests, activities and levels of competence - and the 'meaning' of the network beyond those interests; its identity as an emergent and distinct *strategy* for community work. Groups were not only meant to participate in the network but to understand and embody this meaning.

The network existed as a specific regime of meetings, roles and expectations of work developed by the groups. As it acquired a certain form, new problems stemming from this form emerged, as did new subsequent solutions. In this process of adjustment, it is possible to observe the permanent efforts made to reduce the contingency that a process of contact with external groups involved. The HS shaped the network on the basis of its own institutional requirements. In the initial creation of the network there was a concern for scaling up community-oriented work - making it more transparent and responsive to the national mental health plan. Simultaneously, conditional funding was a tool to rationalise and shape the work of the groups interested in the network. Subsequent adjustments were aimed at reducing the risk of contestation and tension, increasingly immunising the network - and, more importantly, the professionals *in charge* of it - from the potential lack of legitimacy of certain decisions.

A sense of dissatisfaction with the interests and the scope of action of the groups composing the network emerged in several interviews with the professionals; a persistent vision of the network as more than the sum of its parts. However, this 'more' was differently conceived. In terms of the diversity of the groups, the need for unity and a sense of commonality was expressed. In terms of problems of coordination, a degree of cohesiveness among the groups was needed to make decisions. In terms of problems of

selection and funding, local groups were forced to work together on projects that transcended their specific interests. Finally, in terms of the emergence of a similar 'social movement' within the HS, local groups and CMHN's professionals were reminded that community was always larger than any attempt at engaging with it.

Harrison & Mort, discussing the notion of participation in health, suggested the idea that 'representativity' was a technology or device that allowed professionals to retain the ability to value or devalue the contribution of service-users (1997). Instead of asking what it is that is exactly meant by ideas of the 'common', the 'identity' or the transcendental reason for groups to be part of the network, one could see them as a device that allows professionals to cast perennial doubt on the value of local groups while obscuring the contingency and limitations of the network itself. This gave the groups a horizon of work; a goal beyond themselves. However, it simultaneously gave professionals the task of infusing the network with this sense of transcendence. To a certain extent, and paradoxically, professionals took up the task of transforming the invited space into a claimed space (Cornwall, 2004).

According to Lauritzen et al., the 'community construct' is 'an outside that is inside the organisation' (2013, 163). The work of professionals is to educate users in how to 'remain in their paradoxical and impossible position of being a member and a non-member simultaneously to create the form of performance that the organisation desires' (164). The figure of the *network* as intermediation between assumedly independent nodes reinforces this paradox. Users are neither *inside* nor *outside* of the organisation; they populate an intermediate space that, as seen in the results, does not have roots within the organisation and can therefore be denied.

**Conclusion**

On the basis of a case study in Chile, this paper explored the ways in which local health services attempt to 'make contact' with community groups, under precarious financial and administrative conditions. By approaching participation in its initial indetermination and as a time-based, tentative process, we have shown how attempts at making contact lead to unexpected scenarios and problems, and how visions of participation and 'community' precede and emerge in the process.

Following Luhmann's notions of system and environment (Luhmann, 1989), participatory initiatives such as the CMHN can be seen as a way in which the institutions reduce the complexity of community engagement to a

manageable degree. Expanding the network opened a more diverse and complex ecology of groups. Funding was an initial mechanism of selectivity and reduction, but calls for unity and trust can also be seen as further complexity-reduction mechanisms, this time aimed at controlling the potential disruption of the network by its own, legitimate members: community groups.

Dynamics of professional and/institutional control have been observed and denounced by researchers and users (Barnes, 1999; Beresford, 2010; El Enany, Currie, & Lockett, 2013). As seen in the introduction, co-optation and control of users' views and influence is part and parcel of participatory projects (Harrison, Barnes, & Mort, 1997; Harrison & Mort, 1998). Still, in our case, domination should be seen as gradual and tentative, responding to the conditions generated in the course of the project.

Analytically, this calls for the consideration of time as a critical dimension of participation and community/institutions relations more broadly. We argue that time precedes 'themes' or 'opinions' as a structuring dimension of the meaning of participation. Participation means contact and contact supposes time. In this way, participatory efforts appear as sequences of actions and reactions that slowly stabilise contingent regimes of interaction, but whose fragility never quite disappears (Mosse, 2004).

In terms of policy-making, and in the context of growing pressure towards the development of a participatory mechanism for mental health service users, careful attention should be paid to how local-scale participatory initiatives develop over time. This is not in terms of their efficacy or as 'best practices' (Mosse 2004), but as real life experiments that reveal the administrative complexity of participation and allow for the anticipation and management of dilemmas. Emphasis should be placed on the reciprocal learning processes leading to participation, rather than narrow definitions of outcomes. Local specificity should be privileged over scalable participatory layouts.

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# Beyond Participation: Politics, Incommensurability and the Emergence of Mental Health Service Users' Activism in Chile

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## Abstract

Although the organisation of mental health service users and ex-users in Latin America is a recent and under-researched phenomenon, global calls for their involvement in policy have penetrated national agendas, shaping definitions and expectations about their role in mental health systems. In this context, how such groups react to these expectations and define their own goals, strategies and partnerships can reveal the specificity of the 'user movement' in Chile and Latin America.

This study draws on Jacques Rancière's theorisation of 'police order' and 'politics' to understand the emergence of users' collective identity and activism, highlighting the role of practices of disengagement and rejection. It is based on interviews and participant observation with a collective of users, ex-users and professionals in Chile. The findings show how the group's aims and self-understandings evolved through hesitations and reflexive engagements with the legal system, the mental health system, and wider society.

The notion of a 'politics of incommensurability' is proposed to thread together a reflexive rejection of external expectations and definitions and the development of a sense of being 'outside' of the intelligibility of the mental health system and its frameworks of observation and proximity. This incommensurability problematises a technical definition of users' presence and influence and the generalisation of abstract parameters of engagement, calling for approaches that address how these groups constitute themselves meaningfully in specific situations.

*Key Words:* Service-user organisations; Mental health systems; politics; reflexivity; incommensurability.

*Declaration of Interests:* None.


**Introduction**

*A voice out of place*

It was three days after I returned to Chile for fieldwork. A colleague invited me to a seminar called 'Stigma towards Mental Illness: A Public Health Challenge', hosted by the historic Dr. Salvador Allende School of Public Health. It was the second event of its kind, and the focus was placed on concrete policy recommendations through case studies coming from different experiences in Chile and abroad.

The programme included keynote presentations by international and local experts, and results from a pilot study on peer-support strategies, developed in Santiago. Inside the large auditorium, there were around 400 people, mostly professionals working in the public system looking for new trends, but there were also academics, students and representatives from NGOs and community organisations. The first presentation was given by a North American expert, speaking in Spanish with slides in English. When it finished the audience was invited to ask questions.

Ramon, an activist and ex-user that I was supposed to meet that day, raised his hand first. He introduced himself as 'a mad person', causing surprise and smiles. He criticised the use of English in a seminar given to a Spanish-speaking audience, and then he questioned the intentions of the presentation, asking to what extent anti-stigma campaigns, and the idea that mental health conditions are just like any other condition, relied on a reductionist biomedical conception of suffering and was a way for the pharmaceutical industry to make their products more acceptable for the population.

The organisers, seated close to me, were clearly uncomfortable with the situation. Their discomfort was compounded by the resounding applause that Ramon received after finishing his observations, with people saying 'that is true', 'he's right' or 'he's very brave!'. The presenter apologised for using English and attempted to demonstrate his user-movement 'credentials', highlighting his long-term work with user organisations in New York. The following presenters picked up the theme, expressing in different ways that purely medical perspectives had limits and that more voices needed to be included, especially the voice of users. It was striking to see how, suddenly,

the voice of 'the mad' mattered, how a presence became perceptible, forcing the experts to make some room.

The last presentation of the day described a local pilot study testing the Critical-Time Intervention (CTI) model, a peer-support strategy developed in New York during the mid-1980's to reduce rehospitalisation rates after discharge (Susser et al., 1997). The presentation included testimonies from users working as peers. As soon as it finished, Ramon raised his hand again. Instead of praising the involvement of users he asked about the earning gap between them and professionals in the pilot, stating that participation makes no sense if it is on the basis of unfair and paternalistic working conditions.

Nobody seemed eager to address the question and there was no applause. People near me said 'does that really matter?', 'isn't that too much?' or 'he's just a *chaquetero*[(1)]'. A user working in the pilot replied to Ramon saying that the money was fine for him and that being a peer in the project was far more important than the income. He received the applause this time, other questions came and the seminar moved on. But what does such change reveal?

Although controversial, the first remarks expressed a sense of rebellion that appealed to the audience and shifted the subsequent tone of the meeting, itself a microcosm of the mental health field and its main publics. Ramon's voice was given a place. But when he interrogated the very role of users and the terms and conditions defining their 'participation', he both transgressed and revealed the limits of that place. His controversial perspective was accepted and supported, but he was not expected to question the role that was already afforded to him. Paradoxically, the mad person lost his role when he reflexively questioned it.

For Jacques Rancière what makes a conflict *political* is not a clash of interests or perspectives but a disagreement about the legitimate parties in the conflict itself. The tension contained in Ramon's second question could not be reincorporated into the meeting as a 'perspective' because it expressed a clash between logics, between ways of defining who had a part and on what terms. The question introduced an incommensurability to the apparently unified horizon of the meeting, an outside that revealed the meeting's 'public transcript', that is, the framework of expectation and the order of roles constituting it as a social space (Scott, 1990). Only from the outside could the meeting itself be observed as a contingent scheme of roles and asymmetries. Only through excommunication could the mad person communicate himself.

This article examines the ways in which activists and user groups develop a vision of themselves and dispute their definition in front of other

agents and their logics. In the following section, the global and local framings around users' collective actions are described and the literature from the social sciences is considered, in order to re-specify the aim of the article.

*Emergence between global calls and local expectations*

In South America, the organisation of mental health user groups and their involvement in policy and/or activism constitutes a recent and under-researched phenomenon. While the call for users' involvement is common in mental health plans and in declarations from authorities, user groups are generally placed within an undifferentiated 'civil society' (Montenegro & Cornish, 2017), whose role is to support specific reforms in the region (Ceriani, Obiols, & Stolkiner, 2010; Montalbán, 2013; Zaldúa et al., 2012).

On a global scale, several agents have called for the empowerment and involvement of user organisations at all levels of policy making. The World Health Organisation's new Mental Health Action Plan 2013 - 2020 has identified new constituencies and leadership roles in the field, within and across countries, including users' organisations, described as crucial agents with a stake in policy, and calling for national mental health systems to strengthen them (2013, p. 12). At the same time, the Convention on the Rights of Persons with Disabilities (CRPD) has given unprecedented centrality to disabled people's organisations, including persons with psychosocial disabilities (Minkowitz, 2013). Traditional organisations in the field have also developed guidelines on working with user organisations (Wallcraft et al., 2011), identifying them as a key ally in tackling stigma and discrimination.

But studies coming from the social sciences –including user/survivor research- problematise the technocratic framework of these global calls, tracing the political and institutional forces shaping the organising efforts of users and survivors and highlighting the power imbalances that limit their scope of action (Barnes, 1999a, 1999b; Beresford, 2010; Brosnan, 2012; Carr, 2007; Lewis, 2014). Users' advocacy efforts are linked with broader social, cultural and political dynamics that transcend the mental health system's declared interests or expectations (Crossley, 2006a; Everett, 2000; Morrison, 2005), interests that, in most cases, constitute the very objects of contention and dispute in the hands of user groups. That means that the actual organisation of users cannot be simply seen as an implementable 'feature' within a technical definition of mental health systems, or deduced from a normative vision of who is or who should be an agent in the field.

Generally, these analyses trace the organising efforts of user groups as they emerged and consolidated in the English-speaking world, where such

practices have a relatively long history (Campbell, 1996; Crossley, 2005, 2006b). In Chile, as in most of South America, there is no 'original' user movement serving as a standard to understand variations over time, or to estimate and theorise the effects of broader social, political or economic processes. As revealed by Ramon's intervention, the role of users and the meaning of participation are at stake, with no clear definition coming from policy (Contandriopoulos, 2004).

In order to understand the specific politics of service-user activism in a new context, and the way a collective identity is produced and projected into society, a more abstract conceptualisation of power and resistance becomes necessary, one that can guide the ethnographic unpacking of positions and identities. Rancière's (1999) distinction between 'politics' and 'police' represents a valuable alternative.

Although developed in the context of a complex discussion against political philosophy, Rancière's work has gained traction in the analysis of the politics of marginalised groups (Dornhof, 2011; Jazeel, 2015; Klee, 2013; May, 2008). For Rancière, 'police' is, fundamentally, the practice of matching groups to functions and activities, or the identification of groups according to the function they accomplish in any given 'community'. 'Police' proceeds as a determination of what each group 'is'. (…) 'it is an order of the visible and sayable that sees that a particular activity is visible or not, that this speech is understood as discourse and another as noise' (Rancière, 1999, p. 29).

> The essence of the police is to be a partition of the sensible characterised by the absence of a void or a supplement: society consists of groups dedicated to specific modes of action, in places where these occupations are exercised, in modes of being corresponding to these occupations and these places. In this fittingness of functions, places, and ways of being, there is no place for a void. It is this exclusion of what 'there is not' that is the police-principle (Rancière, 2010, p. 21).

In the face of police runs a counterforce, 'politics', a struggle against the distribution of parts and roles, announcing the gap between beings, places, and functions from a position that is not yet distributed, from what does not fit, from a void. Politics is 'the production of a series of actions of a body and a capacity for enunciation not previously identifiable within a given field of experience, whose identification is thus part of the reconfiguration of the field of experience' (Rancière, 1999, p. 35). In Connor's interpretation, 'politics is an interruption into the realm of what exists, in its divisions and parts' (2014, p. 11).

During the seminar on stigma, Ramon's final words came from a place that did not have a place, revealing a capacity that was not yet visibile, a capacity to reflect upon its own role and value. As a carrier of a vision of himself, he became 'excessive', beyond the boundaries of the 'acceptable' mad voice. But how do activists collectively reject expectations of policy? How do they create a place of their own?

This study looks at the politics of the mad in the context of the ordering forces of 'police': the actions through which organised users in Chile reflexively shape their own collective identity and dispute their own position. Based on ethnographic fieldwork with Ramon's organisation, it considers the practices through which user groups orient themselves, project themselves and sustain their own difference against other agents' and systems' frameworks of legibility and approachability.

## Methods

There are multiple expectations about the role of user groups in the mental health field, influenced by global calls and international examples, mobilising agendas and opportunities for users but also shaping a definition of their role and contribution. Methodologically the challenge is to get closer to the organised efforts of users and see how they read such complex environment. A focused ethnography (Knoblauch, 2005) was chosen as a research strategy, focused precisely on how one such group projected itself in the field and defined its own meaning and goals. The ability to focus the ethnographic attention upon specific aspects and events relies on the researcher's accumulated experience and expertise in their field (Knoblauch, 2005).

Before starting the fieldwork, I contacted currently active user-led advocacy initiatives without the mediation of local and national health authorities or professionals. This was partly facilitated by prior links with members of those organisations through the years in my position as a social researcher and academic within the Chilean mental health field. Three organisations were initially contacted: the National Association of Users of Mental Health Services (ANUSSAM), 'Radio Diferencia' (RD) and 'Agrupación Libre-Mente' (ALM).

ANUSSAM, the oldest user organisation in the country, was born in 2000 out of a confluence of interests between the Mental Health Department of the national Ministry of Health and a group of users participating in CORFAUSAM, a coalition of family organisations (Montenegro & Cornish, 2017). In the typology of the mental health system, ANUSSAM is the only organisation

representing the interest of users at a national level. ANUSSAM was ruled out for this study because the frequency of meetings and activities during that time was very sparse and strictly linked to the formal need to select a new board. There were no other plans or relevant activities and even during those few meetings only a fraction of the members participated.

Radio Diferencia is a radiophonic project born in 2005 led by a group of users of the El Salvador psychiatric hospital in Valparaiso. Defining themselves as 'the voice of those without a voice', it produces several radio shows with different thematic segments led by users, with the aim of educating the public about the rights of persons with psychiatric conditions, in order to dispel the myths around mental illness. They usually invite authorities, activists and all sorts of experts to speak on the show: The first time I met them I immediately and unexpectedly became an interviewee. However the activities of RD were strictly related to the production of the show. Moreover, the fact that the show was produced in the facilities of a psychiatric hospital further limited their range of opinions and oppositions. The most relevant insights came from individual conversations with their members after the show was over.

ALM was the only group who explicitly organised their meetings to be open to anyone. They were engaged in a series of relevant activities that multiplied the possibilities of engagement beyond the meetings, such as demonstrations, participation in events, meetings with other groups, etc. The more I was exposed to their activities and plans, the better I came to capture a sense of continuity and maturation. Gradually, during the course of fieldwork I decided to follow them closer, wrapping the research project around them.

Concretely I participated in 17 meetings with ALM and I joined them in several informal activities. That includes regular weekly meetings (9), extraordinary meetings -focused on specific projects- (2) and events and activities where members acted as representatives of the group, together with other user groups and supporters (6). It amounted to approximately 70 hours. In addition, I conducted personal interviews with five users engaged in the group (5). Field notes recorded the conversations that took place during the meetings, focusing on how the group described its own goals and positioned itself in front of other, relevant agents and agendas. In parallel, I closely followed the posts and debates produced by the group through their Facebook page, before and after fieldwork, maintaining regular online contact with some of its members to this day. I also participated in meetings and activities with the other two organisations (7) conducting interviews with their members (10), which helped me to better situate the position of ALM in a larger and diverse network of activists.

Fieldnotes, audio recordings and transcriptions from interviews were integrated into a qualitative software package (MAXQDA12) to assist the analysis. Thematic analysis was used upon these sources, with a coding framework combining deductive and inductive themes. Participant observation had precedence in the analysis and in the findings, and therefore the results follow a sequence of activities that concentrated the energies and reflections of the group during fieldwork. These activities linked the group to (i) the legal system, (ii) the mental health system and (iii) society at large. After first introducing the characteristics of the group, the findings section deals with each of these realms.

Written consent was received before every individual interview. In the case of the meetings, their composition changed permanently, therefore at the start of each meeting I made my aims explicit to old and new members. The group fully supported my project during the process, and I was granted permission to audio-record most of the meetings, enhancing the analysis of field notes, in line with the principles of focused ethnography (Knoblauch, 2005; Wall, 2014).

The focus of the project is on how the group creatively and reflexively negotiated its collective identity, regardless of each member's specific background and/or circumstances. The main insights come through open, spontaneous discussions that involved most of the members, both old and new. Although aware of my aims, due to the changing composition of the meetings, not all the participants gave written consent to be identified in my research. Therefore, both for analytical and ethical reasons pseudonyms are used in the article.

**Findings**

*The group*

In early 2015, I got in touch via email with Agrupación Libre Mente through Ramon, an ex-user and disability rights activist whom I had met in 2014, in the context of my involvement in the Quality Rights project where professionals and users evaluated mental health facilities across the country (Minoletti et al., 2015). He discussed my project with the other members and he replied that they were OK with me coming to their meetings. I arrived in Santiago by the end of July 2015 and 3 days later I attended the previously described seminar. I did not know Ramon was going to be there.

That day, during lunch, I approached him and Claudio, another member of ALM, and we talked for a while before other people circled them to ask them

questions. It was Monday, the day ALM met, so they invited me. The meetings were held on the second floor of Librería Proyección, a busy anarchist bookstore located on the side of the colonial San Francisco church, in the heart of the capital.

Libre Mente was born in 2013. The group resulted from the transformation of a prior 'auto-formación' [self-training] initiative led by psychologists and other young professionals. It was directly connected with the work of the Centro de Acción Crítica en Salud Mental [Center for Critical Action in Mental Health], an active group within the burgeoning 'anti-psy' scene in the country. Antipsychiatry and 'anti-psychology' have had a resurgence, particularly in academic psychology, through the work of Chilean philosopher Carlos Perez-Soto (2014) among others. This Marxist, anti-capitalist form of anti-psychiatry resonated with the values of a generation of students that participated in the waves of protest sweeping the country over the last decades (Cabalin, 2012).

Ramon, an active member of the disability-rights scene in the country, was the first member of the group with 'a direct experience of psychiatrisation' (his words). Although his aim was to shift the group towards a user and ex/user based initiative, for him, service-user exclusivity was pointless: the group saw itself as the outcome of solidarities across the user / non-user divide, as in other Latin American countries where mental health activism is diverse by definition (Freitas, 2011). This is why initially the group called itself a 'Movimiento de Personas por la Salud Mental' [A People's Movement For Mental Health].

Through 2014 Ramon also formed the 'Locos por Nuestros Derechos' [Mad for our Rights] collective, an advocacy initiative responsible for the Manual de Derechos Humanos en Salud Mental [Human Rights in Mental Health Handbook] (Locos por Nuestros Derechos, 2015). He had already visited mental health services, universities and diverse community organisations across the country and internationally, disseminating El Manual and offering his critical views around forced and irreversible treatments, the medicalisation of children's behaviour, the role of pharmaceuticals in influencing policy and the unacceptable complicity of professionals. Users, students and professionals generally wanted to know more and in response an open invitation was extended to ALM's meetings.

The diffusion of El Manual prompted a circulation of participants into the meetings, mostly psychology, social work and occupational therapy students, journalists, social scientists, community organisers and activists interested in the group. During fieldwork the number of participants in a meeting fluctuated from 7 to 15. Amongst the permanent participants, there was a group who did

not describe themselves as users, ex-users or survivors. Most of them worked in mental health or related fields, in different levels and locations, and some of them had a longstanding connection with LGBT activism, the student movement or animal rights advocacy. It was a diverse group in terms of age, gender and background, but they all had a wide knowledge of mental health policies, the power of the pharmaceutical industry and the damage that tradition mental health services could do.

There was also a permanent group of users with whom I engaged the most. I interviewed each of them during the first weeks of fieldwork. Renata and Pedro were living together for about a month. Ramon lived with his partner and worked independently in construction, while Pedro and Claudio had met in psychiatric facilities and together sold different products in central Santiago's street markets. Alonso lived with his family and had a job through the intermediation of a local disability office. All of them were acquainted with other users through their paths across institutions and rehabilitation services, inviting them to the meetings.

Almost all of the users had experienced neglect, abuse and manipulation in the hands of psychiatrists and other professionals working in the mental health system. Some had quit all medication, particularly Ramon and Claudio. Alonso was working towards discontinuation, with the advice and support of the group. Yet others, like Renata, openly defended the informed use of psychopharmacological solutions. Among them Ramon had the most distinctively radical stance towards traditional mental health services, using his own life experience to publicly speak against psychiatric abuses. Not all of them shared his vision or intensity. While their stories overlapped, the group had no unified aims.

Each meeting was started by Ramon or other members briefly describing the last meeting's agreements or issues that required follow-up. Then introductions came by new and old members, accompanied by lengthy conversations. The level of attention given to each participant, regardless of how long they had been participating always surprised me, since the moment I introduced myself. More importantly, the diversity of the meetings, with users, ex-users, non-users and uninitiated guests produced a highly deliberative space, where the definition of the group's aims and identity emerged reflexively (Archer, 2007), as an ongoing achievement rather than a starting point. Every meeting re-started the group.

But regardless of the changing composition of each meeting and the countless interesting topics and situations observed, there were three specific projects that demanded more time and energy and required the group to decide on a number of important issues. These projects forced the group to

reflect upon its own identity, that is, on how it was perceived by a set of others, others made relevant by the projects. These three projects provide the 'focus' for the focused ethnography. These were the project for the creation of a coffee shop, the parallel creation of a new national mental health plan, and the planning of the first Mad Pride Parade in Chile. These projects, in turn, involved a process of engagement with the legal system, the mental health system and society as a whole.

*The Legal System*

There were 8 participants at my first meeting including other first-timers. Usually, each new participant was subjected to questions coming from all members. The group interrogated me, demanding more than a repetition of what Ramon had already told them, and I could immediately perceive the importance of testimony and position. The other first-timer was Alonso, a service-user, and he was interrogated about his diagnosis, pharmacological treatment, services being received, interaction with professionals, etc. These extended personal introductions created a sense of presence: we were not 'just' there, to observe or learn, we were part of the meeting with stories and concerns potentially linking us together.

I offered my help with activities. At that point, their main project was the creation of their own coffee shop. Over the next 4 meetings this was the main topic of discussion and planning.

During the first two encounters, the conversation around the project was creative and playful. In the 'imagined' coffee shop every idea made sense, from the most trivial business considerations to the ambitious desire to 'rehumanise the normals' through the cafe [Renata, Woman, 45 y/o, User.]. In contrast to what they viewed as an alienated, individualistic and sad society, the group wanted to create a 'café con-ciencia' [wordplay meaning 'consciousness coffee' and 'coffee with science'], where clients could change not only their opinions about madness but could also experience a sense of personal transformation, the sense of being in the difference.

As such, beside the relevant economic benefits, the project expressed a desire for a meaningful re-engagement with society, reversing stories of miscommunication and alienation:

> This should be a space of expression, not only our expression but the expressions of those who come here (…) It gives us the possibility of listening to the other, in this case, the client, and this is similar to what happened with us and psychiatry because… you go to the doctor and you

want to be heard and he says 'ok, time's up' and that's it [Claudio, man, 55 y/o, ex-user].

Through their plans for the project the group rehearsed notions of shared decision making, horizontality, transparency and democracy. The shop was an imaginary space for them to play with their possibilities of existence as a group. But transforming the utopia into a real place required the adoption of a form. For the project to work, it had to be legally valid, and for this, the group itself needed a *personalidad jurídica*, a legal persona, acceptable by the legal system as a right-and-duty-bearing unit (Dewey, 1926).

It was a big step, so the group sought some technical advice. A coffee-shop owner, an expert in cooperatives and a lawyer came to the meetings. Some members had already created a 'corporation' that could be reactivated, a type of legal persona that allowed them to apply for funding, conduct research, run businesses, etc. Although comprehensive, the corporation required an inflexible set of internal functions and distinctions: between board and associates; president, secretary and treasurer; normal and extraordinary sessions, etc. Another legal persona, the 'cooperative' seemed to better match the self-image of the group, with shared decision-making and equal distribution of work and income. But such form could only be used for very narrow purposes, preventing the pursuit of broader 'social' goals and eliminating the possibility of receiving funding from external agents, such as the State, international agencies and NGOs.

'Once you make a decision about your aims, it will be easier for me to give advice on the best juridical personality' was one of the final remarks made by Hector, an impeccably dressed lawyer invited to the last coffee-shop related meeting. But the selection of a legal form was not a straightforward decision. The proposed project symbolised the group itself, it was an image of how they wanted to be seen, and a way to 'come back' to society on their own terms. But to be viable it required a legal fiction (Dewey, 1926), legible by the legal system, alien to the ongoing self-identification of the group. The group faced a paradox, a potentially endless oscillation between options (Perez & Teubner, 2006): the only way to be what they wanted to be -a financially viable, user-run coffee shop- was to be something they rejected -a corporation with hierarchical roles and internal divisions.

For Teubner, 'Real paradoxes are highly ambivalent. They contain destructive, paralysing potentials but contain at the same time productive, creative possibilities' (2006, p. 48). During the last part of the meeting Claudio made this point:

> So, how to say it, these meetings like the one we're having right now, while not part of a formal legal figure, these meetings place us in a relation, they make us develop a relationship between each other, on another level.

The closer the group got to this dilemma of identification, the stronger the need to acknowledge its own relational reality as already there, regardless of legal identifications. As expressed by Cooper in her ethnography of mental health courts in the San Francisco Bay Area, USA, 'The court's formulation of jurisdiction and its creation of individuated subjects reach an impasse at the moment of the social' (2018, p. 100). In the context of activism, the pre-existence of social bonds provides a foundation for the group to navigate the options of legal identification.

We will return to the fate of this project in the final section of these findings.

*The Mental Health System*

During my fifth meeting with the group, several professionals mentioned the ongoing elaboration of a new national mental health plan. The plan considered a process of country-wide consultation among every level of attention in the public mental health system, including civil society organisations. As a growingly active and visible group in the field, Libre Mente was expected to participate.

As I learned from the person in charge of this plan at a national level, the design of the consultation was very simple. The Mental Health Department of the Ministry of Health sent a draft version and each involved group or agent could discuss it collectively, adding new sections and feeding this back to the Department. Participation in the elaboration of the plan meant engaging in this feedback process, but there were no guarantees or rationale for how this information would be incorporated into the final plan.

Conversations about this consultation re-emerged in several meetings and in the context of different discussions in the group. The issue was originally raised by two professionals who had already participated in the consultation, and by Elisa, a user who was very active in her own Consejo de Desarrollo Local (2) where she learned about the plan. Ramon, on the other hand, had a different view:

> Personally, I don't want to participate in whatever the mental health department wants to do. I mean, because that plan is already decided. What underlies this exercise is the same old approach, four or five psychiatrists, who already monopolise all the decisions, make a deal. The

only thing they want is money for more drugs and treatments, they disguise that with the discourse of rights and users' participation... In the group making the real decisions there are no users, but they want to validate their plan so some users will share their views, and that's why for example Eva, who leads an organisation in Puente Alto, is inviting Elisa who lives on the other side of Santiago so that she can show up as one more user participating and validating the whole thing.

Elisa was a middle-aged woman struggling with her own diagnosis and the sole provider of care for her disabled husband. She was an active member of a 'Local Development Council', the main mechanism of citizen participation available within her health service, and she had successfully brought herself to the attention of care providers, receiving urgently required treatment. El que no llora, no mama ['The crying baby gets the milk'] was her (and many others') leitmotif, and the plan's participatory process was an opportunity to cry and be heard. She confronted Ramon saying that she was the one interested in the process, and she had contacted other persons to look for possibilities of involvement.

But for Ramon there was a deeper concern: 'Who created the first draft? Why them? Why are they supposed to know better? (…) they choose what we're supposed to discuss, 'discuss this and that', what are the concerns, the problems, what are the gaps, etc. They choose the topics, the problems and the words. They choose who's invited to give comments on the draft. They choose what to include from the feedback, they write the final plan and on top of that, they take the credit for being inclusive and participatory!'. In the words of Claudio: 'The problem is that we are just reacting to what they are doing, we should work on the basis of our own work (…) because when we start to engage in a fight with the institution we forget about ourselves'. Rejecting the plan was a way for the group to confirm its own autonomy and value.

Increasingly, the conversation moved into the relation between ALM and the mental health system. For some, the flawed methodology and the dubious intentions of the Plan were precisely the reason why the group had to engage. 'We should at least define what do we expect from the mental health system, what's our ideal', said one of the professionals. For him and others, the group needed ambitions beyond itself. In the metaphorical expression of Valeria [Woman, Psychologist, 30 y/o], while it was fine to raise the pins every time the ball knocked them down, eventually the whole game had to be transformed. The ultimate goal was to transform the mental health system, and not just to help each other to deal with their problems. Ramon responded to this and similar concerns:

Instead of thinking about ourselves working with the institutions, our plan

is to empower ourselves, to define ourselves, to be an agent of change in ourselves, more than waiting in the system because the system is oriented to reproduce itself, and it only works for its own interests (…) So the change has to do with ourselves, how we build a citizen in ourselves, empowered, and we empower other people (…) That's our mental health plan, that's what we need to build. They care about facilities, budgets, drugs, professionals, that's all. They call it 'human rights', they say 'inclusion' because they have to do it, but those are just names.

So instead of changing the game they could rather create and play their own game. For Claudio, 'It's good when we share stories about us helping others, our own reactions to injustice. To the extent to which we as a collective create forms of action based on dialogue and discussion, not like those arbitrary and abstract plans that come from the outside. The advantage in that you start from your reality, not from suppositions about what we, I mean, they need.'

The invitation from the mental health system created an opportunity to paradoxically take distance from that system. By seeing the mental health system as a blind, self-reproducing machine and its participatory plan as arbitrary and 'exterior', the group reflexively recognised its own exteriority in relation to the system. The 'either/or' hesitation between participating or not led to the realisation of their own existence beyond (or outside of) the options, beyond participation.

The plan and the process of consultation required a sequence of activities and a certain temporality (Renedo & Marston, 2015), guiding the actions of the mental health system during a predefined set of years, in line with WHO's and PAHO's health plans for the region (Caldas de Almeida, 2005; Minoletti, Sepúlveda, & Horvitz-Lennon, 2012). If policy plans encode visions of the possible and the desirable (Abram & Weszkalnys, 2011), then what was rejected was also the temporal determination of the possible and desirable for the group. The plan became observable as a technocratic chronology in relation to which they could embrace 'their own plan' for self-transformation, their own notions of betterment and progress, their own distinction between past and future.

For Abram and Weszkalnys (2011) the power of plans relates to their ability to draw different publics into a sequence of actions. In our case, the National Mental Health Plan's aim was also to guide the action of a whole series of agents constituting the system's relevant environment. Rejecting the plan was also a way to avoid a place within that environment. This third process is clearly visible in the next section on the mad pride parade.

Gradually, a decision about the 'legal personality' for the coffee shop became difficult to make. As stated before, the problem was not so much about which legal form to take, but about the need to take one in order to be what the group wanted to be. On the other hand, with its dependency on opaque legal definitions and administrative procedures outside of the group's scope of action, the project was naturally replaced by initiatives that actualised a sense of control, completion and progress. The main new activity was the organisation of the first Mad Pride Parade in the country, La Marcha del Orgullo Loco [3].

Some participants knew about international versions of the parade. Locally, the Parade for Sexual Diversity originally called the 'Gay and Lesbian Pride Parade' mobilised tens of thousands of people every year since its origin in 1999 (MUMS Chile, n.d.). At the same time, recent waves of student mobilisation in the country widely deployed theatrical and carnivalesque resources as a tool to communicate demands of social transformation (del Campo, 2016), providing a relevant symbolic background.

The parade's planning and preparation required many activities and decisions. While Ramon led the process, different tasks were distributed across participants, and all decisions were discussed in the Monday meetings and other extraordinary sessions. The first decision concerned the dates and place. The parade involved blocking key avenues in central Santiago, and a request had to be submitted to the Municipal Authority.

The initial plan was to organise the parade as a counter-manifestation to the International Mental Health Day (10th of October), celebrated since 1992 and initiated by the World Federation for Mental Health to rise the publics' attention towards mental health issues (Brody, 2004). But while a counter-manifestation could enhance the visibility of the group and its claims, for Drago, a user and university student '(…) this manifestation should come from us, not from what they are doing (…) otherwise it would look like we are simply reacting to what they're doing'. Finally, the date was moved to November.

A fixed date and venue were required to start inviting as many people as possible. But who was going to be invited? The mental health system already had a recurrent 'public' (Newman, 2009) assembled around the perennial call for financial resources (Montenegro & Cornish 2017), a call linking global and national agents from the PAHO, INGOs, local NGOs, Family Organisations, and many others. The group rejected this call, considering itself outside of the instrumental version of the public sphere created by the mental health system. Who was represented in the parade then? Only ALM?

Concretely, the initial concern was about who had to be rejected. Political campaigners could use the parade for self-promotion. They had to be excluded or required to refrain from using banners or other messages. But other groups were harder to distinguish, especially NGOs and established family organisations. Ramon suggested that all participants should sign up to a document, adhering to certain principles. The group discarded this as impractical. Others suggested installing a 'press point' where journalists, people from the media and/or any curious people could ask questions and receive agreed-upon information, reducing the risk of both misrepresentation and misinterpretation. Connected with this idea, Julia [Woman, caregiver, activist, 38] suggested a manifesto with the group principles, 'a text that defines who we are and what we want, and well if you disagree you better stay at home'.

Questions about how to present themselves came back to the conversation. But while past hesitations reflexively produced a sense of distance, the nature of the parade required intense engagement and exposure. Not all the interests could be controlled in advance, especially as they unfolded in space, with the multiplicity and simultaneity of voices and orientations that this implies (Massey, 1999). Furthermore, the parade had the power to irreversibly situate ALM in front of other users, professionals, NGOs, the media and society at large. The stakes were high and I could feel how a relentless preoccupation with integrity and autonomy met an equally relentless drive towards the outside, towards the streets, towards the other. How could the group navigate this tension?

Right from the beginning, planning the parade was followed by a secondary, less practical reflection about madness itself. Faced with the question of self-presentation, that reflection became central. Are we mad? Are we proud of it? Is this the word we want to use? Is it actually offensive? For a user in another organisation, celebrating 'madness' was like giving up the battle against prejudice, like saying 'ok, you won, you can call us whatever you want' [Esteban., 27, user]. Even in Libre Mente the issue was not settled. For some the point was to re-signify madness, focusing on the other meanings of loco: Radically original, extraordinary, unpredictable, out of this world, etc.

But Julia's position pointed to another function for the word: 'The thing about 'mad' has to do with who calls you like that. It is one thing when others call you mad, and a different thing if you do it yourself and you do it with pride'. As such, beyond semantics, the word delineates a community for the first time, the community of those who are not ashamed of calling themselves mad. This was not the 'population suffering from a mental health condition' or the 'group

of people living with a psychiatric disability'. Not even the 'representatives from service-user organisations' summoned by a contingent policy requirement.

'Mad' is the word that the mental health field rejects as an expression of ignorance and prejudice. To a certain extent the field itself is founded on this rejection, including groups conflated with users, such as family members and caregivers. 'Your son is not mad, he has a mental illness and there is a treatment' is the statement that constitutes them as caregivers, dispelling any doubt and setting a course for their lives (Montenegro & Cornish, 2015). They, as Claudio and Renata expressed, felt clearly insulted by the name of the parade. But, precisely because of this, embracing 'madness' had the potential to create the kind of alliances and solidarities they wanted to create, to project and protect their difference in the ecology of interests populating the parade, to create a separation, a sphere of validity and expression incommensurable to the field.

## Conclusions

Libre Mente's process of self-differentiation is expressed through instances of hesitation linked with practical activities and aims. These hesitations reveal a practice of collective reflexivity that threads together an orientation towards social transformation and a recognition of the group's value, allowing them to affirm themselves against parameters of proximity and engagement coming from the outside, and to see themselves as incommensurable to those frameworks. Rejecting the legal persona, refusing to engage in the policy consultations and embracing the apparently offensive notion of 'loco' are not just actions chosen out of a coherent pool of options. These decisions shape the group itself, its visibility and compatibility with other expectations and agendas. Broader consequences are elaborated in the following section.

*Activism as a practice of reflexivity*

With few exceptions (e.g. Noorani, 2013) the literature on activism in the mental health field has not placed a strong emphasis on reflexivity. But, as seen in the findings, conversations about themselves and their role constituted an important tool for the group. As stated by Archer in her analysis of collective agency,

> One of the main tasks that reflexive deliberations perform is to enable
> subjects to consider their concerns in relation to their social circumstances
> and their circumstances in the light of their concerns, to revise both

accordingly and then to think of their future courses of action in terms of the revisions made (2013, p. 151).

What the findings reveal is precisely how a series of circumstances required the group to consider its own value and meaning, as a ground from which to observe those circumstances. Reflexivity was a practical tool, a mechanism to overcome dilemmas and paradoxes steaming from external requests. This self-recognition informed different decisions and shaped an ability to make distinctions and to select alliances, invitations and forms of self-presentation. Using systemic terminology, a self-referential tendency (Luhmann, 1995) is the condition of possibility of forms of communication and engagement, a mechanism for the group to not be dissolved in the contingency of interests and frames, expectations and roles defining the field.

*A politics of incommensurability*

Literature on organised activism in mental health has tended to focus on processes of engagement with and influence upon policy processes: Its preeminent concern is the interaction between affected groups and institutions or powerful agents. Critical studies around activism in mental health give attention to logics of professionalisation (El Enany, Currie, & Lockett, 2013; Harrison & Mort, 1998) and co-option (Pilgrim, 2005), but still views them as distortions and deviations from an otherwise desirable growth in engagement, influence and 'proximity' (Bacqué, Rey, & Sintomer, 2004).

This paper, in contrast, demonstrates how practices of disengagement and distancing, what Papadopolous et. al. (2008) call 'exit politics', are essential in the emergence of user's organised actions. In their quest for expression and engagement, users reflexively produce a sense of being 'outside': Outside of the legibility of the legal system and its figures and fictions, outside of the approachability of the mental health system, outside of the temporality of its National Plan and outside of its descriptive ambitions. Even direct opposition is dismissed as mere reaction, favoring what could be called a politics of incommensurability: not just against or in contradiction to any given order, but not mapping into it or alongside it (Lambek, 2012).

'Being outside' has specific connotations in the case of mental health service users, considering that many of them had struggled to get out of mental health institutions in the past. Even in community mental health settings, users become subjects of intensive, prolonged, incongruent and often damaging practices of description stemming from diagnostic models and procedures (Ben-Zeev, Young, & Corrigan, 2010; Moncrieff, 2010; Rose, 2006). Using Rancière's terminology, this practice of description is the

fundamental action of psychiatric 'police' after the asylum. Incommensurability as 'politics' represents the simultaneous suspension of that process of identification, its replacement with a new regime of collective self-identification and the rejection of any auxiliary position in relation to the mental health system. The findings reveal how ALM went through this *political* process. For Rancière:

> Politics begins when those who were destined to remain in the domestic and invisible territory of work and reproduction, and prevented from doing 'anything else', take the time that they 'have not' in order to affirm that they belong to a common world. It begins when they make the invisible visible, and make what was deemed to be the mere noise of suffering bodies heard as a discourse concerning the 'common' of the community. Politics creates a new form, as it were, of dissensual 'commonsense' (2010, p. 147)

Mental health systems see as their goal the alleviation of mental illness and suffering. This reduces the complexity of their potentially immense number of interlocutors and also defines the scope and characteristics of that interlocution (Montenegro & Cornish, 2017). A user is a user because it needs something from the system, and the system approaches users on this basis. The notion of a politics of incommensurability points to the conversations, decisions and gestures by which users and ex-users collectively dispute their intelligibility and approachability. In the terminology of Rancière, it is the process by which a group breaks with its 'destiny' -understood as their expected role- in order to define *their own* role.

*Rethinking participation in mental health systems.*

As indicated in the introduction, the call for users' involvement continues to influence policy making, especially in the English-speaking world but increasingly in countries in the 'global south' (Lempp et al., 2017; Semrau et al., 2016). Reproducing a technical, top-down view of 'involvement', these evaluations see the role of users as one of integration and continuity with the roles of mental health systems, with no tension or opposition between users and mental health systems, and with no apparent differentiation between family/caregiver and user participation. Under the umbrella goal of 'scaling up' services (Semrau et al., 2015) and consonant with the ambitions of contemporary global mental health (Eaton et al., 2011; Patel, Minas, Cohen, & Prince, 2014) these and other studies are setting the standard of evaluation of service-user participation and advocacy in other parts of the world (World Health Organization, 2013).

This case study confronts a reductionist and decontextualised approach to involvement by identifying practices of reflexivity and incommensurability as critical elements in the emergence of mental health users' and ex-users' activism. Incommensurability directly undermines the 'measurability' of users' influence and presence, especially when observed as a component of a modern mental health system.

An undifferentiated call for participation needs to be supplemented by approaches that embrace the variety of forms taken by mental health users' activism in different settings and regions. This means placing the emergence of self-initiated collective action in its own, specific socio-political milieu and historical background. It also means that the disputes, disagreements and opposition should be viewed as central aspects in the analysis of politics and participation in this field (Carr, 2007) and not simply as 'risks' to be avoided. Finally, closer attention to how users and activist make sense of their own role opens analytical ways to critically understand the shifting expectations, dispositions and ambitions of mental health policy, at national and global levels.

## Footnotes

(1) In Chile, 'chaquetero' is someone that expresses harsh criticism out of envy for someone else's achievements or position.
(2) By law each health service in the public health system has a 'Local Development Council' acting in representation of the communities served.
(3) It is important to note that semantically, the word loco is closer to ''crazy'' than to ''mad''. Specifically, the word 'loco' does not denote anger.

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**PAPER 4**

Title: **'Are you a radical now?'. Reflecting on the situation of social research(ers) in the context of service-user activism in Mental Health.**

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## Abstract

The relationship between activism and social research is a longstanding source of debate. In the mental health and disability fields, this tension has specific connotations: User-survivor activism is premised on the priority of first-hand experience over detached, 'objective' knowledge. Personal experience is the foundation for the specific and irreplaceable perspective that users and survivors bring to issues of interest. Considering this, how do user/survivor groups relate and interact with academically oriented researchers without a first-person encounter with psychiatry?

Drawing on the ambiguities surrounding my participant observer role across activist initiatives in Chile and following the call for strong reflexivity in qualitative social research, in this article I retrospectively trace how my interests and presence was received, negotiated and contested by users and non-users in the field.

The introduction contextualises the emergence of service-user activism in Chile. Subsequently, the specific challenges that this form of activism poses to social research are discussed, with a focus on the key role of 'experience' as a legitimate source of knowledge. I then introduce the 'reflexive vignette' as a suitable way of providing a retrospective account of my presence in the field. The results section describes four episodes in which my own status - and that of other researchers - was interrogated and the efforts I made to articulate and legitimate my interests and presence. In the conclusion, I explore some consequences of this, discussing the analytical value of reflexivity in researching activism and the limits of a normative call for a political and ethical alignment between activists and researchers, especially in the context of emergent practices in the global south.

Keywords: Activism; Mental health; Users; Survivors; Reflexivity; Academia; Engagement

## Introduction

Discussions around the continuity or discontinuity between 'activism' and 'academia' - usually with other names - have been part of the social sciences since their inception. This tension has specific characteristics in the context of mental health service-user activism, where priority is given to first-hand experience over detached, 'objective' or 'professional' knowledge (Noorani, 2013). First-hand experience is usually a marker of membership across activist groups and the foundation for the specific and irreplaceable perspective that users and survivors bring upon issues of interest. How, in this context, do service/user groups relate and interact with academic research? How are the boundaries between research and activism negotiated?

Over the last eight years, I have worked in mental health settings and conducted research about different social aspects of the Chilean mental health field (Mascayano & Montenegro, 2017; Montenegro, 2011; Montenegro & Cornish, 2015, 2017). In 2015, I spent three months participating in the activities of Agrupación Libre Mente (ALM), a user-led activist organisation in Chile, with the aim of understanding their main concerns, aims and forms of collective action. My goal was to produce an account of their actions *from the inside*, beyond diagnostic determinations.

A central finding was that, through different actions and decisions, ALM calibrated its own approachability *by others*, exercising a reflexive capacity for self-differentiation in response to external definitions and expectations about their role (Montenegro, 2018). Yet, to an important extent, my presence and the negotiation of my research interests within the group represented an instance of the same process of self-differentiation, an opportunity for the group to perform its own boundaries and, for the same reason, a window into how the boundaries between activism and academia are negotiated in practice.

Following Devereux, in this article I want to retrospectively unpack the production of an 'observational situation' (1967) between me and the activist group that I followed through fieldwork, to trace how my interests and my presence were received, negotiated and contested. Using the 'reflexive vignette' (Langer, 2016), I present four fieldwork episodes in which my status - and that of other social researchers participating in the group - was interrogated, and the efforts I made to articulate the legitimacy of my interest and to secure the continuity of the engagement. In the conclusion, I explore some consequences of this process, highlighting the value of self-reflexivity in researching activism and situating my experience in the context of debates about the role and legitimacy of social research vis-a-vis service-user activism

(Cresswell & Spandler, 2013; Rose, 2008a; Russo, 2012; Russo & Beresford, 2015).

*Activism and the Chilean mental health field.*

While the autonomous organisation of mental health service users and survivor groups is a stable feature in different countries of the northern hemisphere, in Latin America this is a recent and under-researched phenomenon. Available studies and policy documents usually place the actions and concerns of organised users alongside mobilised professionals, caregivers and other allies under a common horizon of advocacy, usually oriented towards the expansion of mental health services (Ceriani, Obiols, & Stolkiner, 2010; Zaldúa et al., 2012). However, during fieldwork I was able to witness an intense politics of dealignment: Between users and families, between users and advocators, and between different user groups with opposing political orientations (Montenegro, 2018).

The first expressions of service-user collective organization in Chile began in the late 90s with the creation of the National Association of Users of Mental Health Services (ANUSSAM). ANUSSAM was the outcome of the efforts of users working in high profile family organisations born in the context of deinstitutionalisation (Montenegro & Cornish, 2017). The legal consolidation of this process required the definition of mechanisms to legitimise coercive measures in the community. The 'Commission for the Protection of the Rights of Persons with Mental Illnesses' was thus born, requiring the representation of a service-user organisation alongside other professional groups (MINSAL, 2000). The match between this legal demand and the prior organising efforts of users within family organisations gave birth to ANUSSAM (Montenegro & Cornish, 2017).

Since its inception in 2001, ANUSSAM has become the formal user-led advocacy organisation tasked with representing users vis-a-vis different government agents, including the Ministry of Health and the National Disability Service. However, over recent years alternative expressions of activism have emerged at the margins, under the influence of two relatively distinct processes. On the one hand, the disability rights movement has had a growth of support over the last few decades, particularly after different Latin American states signed the Convention for the Rights of Persons with Disabilities (CRPD) (Angel-Cabo, 2015; Figueroa, 2017b). Several efforts have been made to harmonise national legal frameworks and the Convention, with a parallel articulation of advocacy actions across the country. In Latin America mental health issues are usually framed as psychosocial disabilities and, through this lens, the vocabulary and political horizon of the CRPD have penetrated debates about mental health services and the right of self-

determination, self-expression and the autonomy of users (Figueroa, 2017a; Minoletti et al., 2015; Observatorio de Derechos Humanos de las Personas con Disacapacidad Mental, 2014).

On the other hand, a burgeoning 'anti-psy' scene has emerged in the country, particularly within academic psychology, through the work of Chilean philosopher Carlos Pérez-Soto (2012) and the critical community psychology of Domingo Asún and others (Domínguez, Kornblit, Rovira, & Asún, 2002). Their work has interpreted and mobilised a sense of exasperation against the role of psychological knowledge and techniques in the production of 'neoliberal subjects' adapted to post-dictatorship Chile, in the school, at work, etc (Pavón-Cuéllar, 2017). Simultaneously, these ideas have resonated with the political values of a generation of students who participated in the waves of protest sweeping the country over the last few decades (Cabalin, 2012).

Both scenes set the context for understanding the political and organisational style of Agrupación Libre-Mente and its vision of mental health institutions and professionals, aspects that are developed in subsequent sections. Prior to this, key elements in service-user activism are discussed, in order to situate the role of social research as it approximates this field.

*Tensions between academia and activism*

The relationship between academia and activism has been debated since the origins of the social sciences. While Marx and Engels' dialectical materialism was simultaneously a science of society and a tool of its transformation (Engels, 2012; Marx, 1990), Weber claimed that science and politics responded to different vocations, irreducible *calls* linked to differentiated spheres of action in modernity (Weber, 2008). Recent calls for activist scholarship have questioned these boundaries (Maxey, 1999) through integrative epistemological and methodological frameworks (Croteau, Hoynes, & Ryan, 2005; Hale, 2008; Smith, 1990).

Activism itself is a very wide concept that includes different goals, strategies and scales. While in many cases a shared vision of social transformation allows for the integration of academic and activist orientations, in other cases knowledge and expertise themselves are key objects of contention, such as in the mental health service-user and survivor movement (Coleman, 2008; Everett, 2000).

In the Anglo-Saxon context, where autonomous service-user advocacy groups have existed for several decades (Campbell, 1996; Crossley, 2006; Huges, 2006), user-produced knowledge and 'lived-experience' are a

fundamental aspect of their struggle (Rose, 2008b). For Faulkner, engaging in knowledge production 'has the potential to empower people, in that it gives us the opportunity to, as it were, reverse the "research gaze" and to use research for our own purposes' (2010, p. 37). While lived-experience overlaps with the so-called 'era of the patient' in medicine (Reiser, 1993), in the context of psychiatry it not only enriches a clinical approach, but becomes a fundamental ground to dispute the authority of psychiatric knowledge and the very notion of 'the patient' (Lester & Tritter, 2005; Noorani, 2013).

The specific perspective that service-users bring to matters of shared concern is based on their direct experiences of use and abuse at the hands of service providers and broader institutional regimes. The centrality of lived-experience complicates the simple crossing of activist and academic boundaries. This has prompted the creation of hybrid platforms such as Mad Studies, defined as 'a project of inquiry, knowledge production, and political action devoted to the critique and transcendence of psy-centred ways of thinking, behaving, relating, and being' (Menzies, LeFrançois, & Reaume, 2013, p. 109). Setting a distance from anti-psychiatry and other form of intellectual polemics, Mad Studies 'takes as its principal source, inspiration, and raison d'être the subjectivities, embodiments, words, experiences, and aspirations of those among us whose lives have collided with the powers of institutional psychiatry' (Ibid).

Although Mad Studies exemplifies a way of understanding the relationship between political and academic commitments in the field, it is still a very localised enterprise mostly situated in English-speaking countries. On the other hand, the relationship between 'experience' and expertise has been debated (McKevitt, 2013; Meriluoto, 2017). Experience is a heterogeneous category whose form and validity are associated with other markers such as class, gender, etc. (Kelly, 2017). The position from which an experience is conveyed is not unitary, receiving modulation by the practical situations taking place to an individual or a group (Jones & Kelly, 2015). As stated by Schrader et al., the 'mad' identity that some of these movements claim is not an intrinsic, defining feature but an 'active and thoughtful positioning of the self with respect to dynamic social narratives regarding mental difference and diversity' (2013, p. 62).

Across the Global South, small scale experiences of service-user activism are emerging; responding to local concerns, drawing on different forms of solidarity and developing unique trajectories of self-differentiation that reconfigure the links between experience, perspective and membership. What is the situation of social research(ers) in these processes? How do these groups deal with the concrete presence and the interests of academics? What

does this say about the way the relationship between activism and academia has been conceptualised in western countries?

Rather than a thorough answer to these questions, this paper instead offers a set of reflections based on my own academically oriented engagement with a group of service-user and non-user activists in Chile. Using this experience and broader observations about the interaction between this group and other researchers, I aim to unravel the ways in which the boundaries between activism and social research are being drawn in this specific field. Although deeply testimonial in nature, the findings are modelled around the 'reflexive vignette' (Langer, 2016), a methodological and analytical tool for the retrospective reconstruction of the interaction between researchers and persons and/or groups in the field. This tool is described in the next section.

*The function of reflexivity and the research vignette*

Although reflexivity has long been part of the toolbox of qualitative social research, recently there have been attempts to problematise its scope. Especially in health, the notion has been formalised as a way to reduce bias and recognise the influence of the researcher in the field, a definition that Kuehner et al. call 'weak reflexivity' (2016). Against this trend, Hervik states that, more than scrutinising the position of the researcher and its effects upon what he aims to describe, reflexivity 'is *part* of the intersubjective context of the fieldwork' (1994, p. 60).

According to Hammersley and Atkinson, during fieldwork, the researcher 'will be channelled in line with existing networks of friendship and enmity, territory and equivalent "boundaries."' (2007, p. 59). This is particularly relevant in the context of emergent forms of activism, where boundaries of political affinity and solidarity are in the making and where the value of 'research' itself is disputed. This is why a careful consideration of the dynamics of encounter, insiderness, and outsiderness *experienced* by the researcher is not a supplement to the description of practices (Labaree, 2002) but rather a source of valuable information about the tensions that define activist spaces (Casas-Cortés, Osterweil, & Powell, 2008; Lichterman, 2017).

Langer's 'Research Vignette' is an attempt to operationalise this form of reflexivity (2016). In its most basic form, the vignette is the description of specific episodes experienced while conducting research. It is grounded in an understanding of interviews and other methods as instances of situated and shared construction of meaning and is a mechanism to place the experience of the researcher as an object of research or, at least, as the basis for further discussion.

This retrospective self-observation is not developed from a fixed or secure position. For Langer, 'reflexivity does not refer to a solid researcher subject but has to consider that this particular subject is constituted performatively in the interview interaction with the interviewee' (p. 745) or, as in my case, in the process of participant observation. It is precisely this unsettledness of the research-position that becomes a source of information about the field. For Devereux, whose work directly inspires this call for stronger reflexivity, a primary source of data for the social scientist is 'the behaviour of the observer: His anxieties, his defensive manoeuvres, his research strategies, his 'decisions' (= his attribution of meaning to his observations)' (1967, p. XIX).

After introducing the setting and the group that I engaged with, I present a sequence of four vignettes taken from the field, chosen for their ability to illuminate the ways in which the group responded to and negotiated the presence of external agents, including myself. These situations created the need to carefully and strategically consider what the group thought about me. In this sense, they represent the simultaneous experience of being an observer of the group and an object for the group's observation.


**First Contact**

Between July and September of 2015, and in the context of a larger project about the emergent forms of users' collective organising in the Chilean mental health field, I conducted participant observation with a user group named Agrupación Libre Mente (ALM). They were engaged in a series of relevant activities that allowed many opportunities of engagement. The more I worked with them, the better I came to capture a sense of growth in their actions and ideas so, in the course of fieldwork, I decided to centre part of my project on them.

I first contacted ALM through Ramon, an ex-user and disability rights activist whom I had met a year ago in the context of my participation in a study evaluating the quality of care and the respect of the human rights of users across mental health facilities. At the start of my PhD, in late 2014, I discovered he was participating in a user-led organisation. After talking with him via email he discussed my intentions with the other members, replying that they had no problem with me attending their meetings. I flew back to Santiago by the end of July and three days later I attended one of the group's meetings.

In our initial conversations with Ramon, we accorded that I could help with the project of starting a coffee shop for the group. This gave me access to the group meetings and also to extraordinary meetings related to the project. I participated in 17 meetings with ALM, conducting interviews with user-members and joining them in different informal activities. In parallel, I closely followed the posts and debates created by the group through their Facebook page, before and after fieldwork, maintaining regular online contact with some of its members to this day. Simultaneously, I participated in activities and conducted interviews with members of two other user-led organisations.

**The group**

ALM was the result of the transformation of a prior group composed of psychologists and other young professionals engaged in the growing 'anti-psy' scene in the country, which some of whom still participated in. Among them, Ramon was the first member with direct experience of psychiatric services. His aim was to transform the original group into a user-oriented initiative, but from its beginnings in 2013, ALM was open to anyone interested, including me.

During fieldwork, the number of participants fluctuated between 7 to 15. Those who did not describe themselves as users or ex-users worked in mental health or related fields, in different levels and locations, and some were linked to other forms of activism. In terms of age, gender and background, the group was very diverse.

Those who described themselves as users and ex-users in the group shared stories of neglect, abuse and manipulation by mental health professionals. All of them were working to regain control over their lives. Still, their perspectives on mental health and psychiatry were not unified, and there was no set of defined and agreed upon principles among them. Above any other goal, they wanted to be together and to keep the group alive.

In one of our first conversations, Ramon emphasised how the meetings of the group provided a space of authentic encounter, beyond clinical expectations and definitions, and how that was the only foundation for empowerment and collective agency. Several months after my fieldwork concluded, and while walking together in London to a meeting with local user activists, he was concerned about the sudden increase of researchers and other 'non-users' in the meetings. Long-term user-members felt increasingly alienated from the space and were thinking about having their own separate

meetings. My engagement with the group broadly coincided with this growing concern, a process that the following vignettes aim to reveal.

**Vignette 1: The students**

At the time of my fieldwork, ALM met regularly every Monday, at an anarchist bookstore in central Santiago. Although there was no predefined structure, each meeting started with a brief account of past issues requiring follow-up. The following round of introductions could take up half of the meeting, that usually lasted two and a half hours. The introductions provided themes and issues to be debated at length. Each participant, old or new, received the same level of attention by the group. In many cases, the stories and ideas of new, previously unknown participants became the centre of much of the conversation. As stated in another paper (BLINDED), the diverse composition of the meetings, involving users, ex-users, non-users and guests, produced lively conversation.

Two psychology students came to one of the meetings with a series of questions about the group. A social psychology assignment required them to investigate an 'active minority'. While Ramon kindly commented that the group needed to decide upon its participation, they insisted. The group finally accepted, and an agreement was made that some of their research questions could be answered via email, to decongest the meeting.

Following this 'interruption', the conversation moved to the organisation of the Mad Pride Parade, the first of its kind in the country. Initially, the main concern was the use of the word 'mad', and the risk of offending and alienating potential participants, especially other users. The conversation revealed wide differences of opinion, and this drew the attention of the students, who they re-engaged in the conversation, as revealed by the following excerpt.

> Student 1: I hear you all and I see that everybody has a very specific perspective. How do you manage to have a shared view of social or other problems?
>
> Valeria [psychologist and long-term ally]: You mean how do we reach a consensus?
>
> Raul [psychologist and long-term ally]: We just know each other for a long time and slowly we have developed certain ideas together.
>
> Student 1: I understand that the meetings are important and that you know each other and all that, but where do your ideas come from, do you take lessons somewhere?

Raul: Look, here the craziest teach the least crazy ones, that's it.

The scripted questions contrasted with the flow of the conversation. Other participants began to talk to each other simultaneously; something that rarely happened. The students directed their questions to the members they thought were most fit to respond: Raúl, a psychologist and ally, and Ramon, who made permanent efforts to distance himself from a position of representation or leadership. The questions revealed a view of activism as depending on a unified set of aims, with the meeting acting only as a medium of those aims. They wanted to define the group through its aims; they wanted to trace it back to its shared position on different issues.

Still, the group defended a degree of opacity. At some point in the conversation, there was a discussion about who should be invited to the parade and about the risk of appropriation of their voices and identity, considering that the parade was open to everybody and that the point was to gather both people and support. The students expressed their desire to be there, to which Claudio responded, partly joking: 'but in the Parade, we only accept participants, not observers'.

On another point, Mariela, who was there for the first time, asked the students if they were only interested in the group because of their assignment or if they had some sort of personal connection with madness and/or mental health, a question that I faced many times. The students tried to address the point by saying that their academic training was very 'critical', giving details on some of the authors they were studying, to which Mariela replied 'in any case, you should be involved with the group beyond that assignment of yours… that could actually make you better psychologists'.

This episode revealed the discontinuity between the group and these untimely observers, their questions and presuppositions, highlighting the unsettled status of research vis-a-vis activism. Simultaneously, it showed how a 'personal connection' with madness gave validity to academic curiosity and was placed above any other marker of professional legitimacy. This anticipated some of the issues that I would face afterwards.

## Vignette 2: The professionals

In the meetings, professionals were usually dealt with through the function they accomplished for the group. Earlier on, somebody brought a perfectly dressed lawyer to advise the group around the legalities surrounding the creation of the coffee shop. Several attempts to incite a more 'human' side

to him failed, such as jokes about the legal profession or comments about the need to update the dress code for the meetings. A personal connection was not required for him: he knew things the group did not, things the group needed to know, and, on that basis, he had a place in the meeting,

It was different for psychologists and other mental health professionals. They needed some additional legitimacy to be there. Usually, they achieved this through a self-critical stance. Some expressed a desire to learn about real people in order to overcome the boundaries and assumptions of academic psychology. Others assumed a more radical approach, denouncing psychology as an aide of neoliberalism and framing their work as one of assistance to the revolution of the mad. Still, beyond these 'diplomatic' or 'critical' positions, they could still rely on psychology to negotiate their presence in the group.

Two weeks after the episode with the students, a new participant came, exemplifying a different way to deal with the problem of 'profession' in the context of the group. She was around 30 years old, and she explained that although she had suffered a mental breakdown at an early age she did not consider herself a service-user. She had studied sociology but never saw herself as one. She was just a person that, at the moment, was exploring the healing powers of plants. Most of the members shared a complicated disdain for medicine. The idea of finding cures for personal ailments without relying on what they called 'pharmafia' produced an intense conversation.

Renata, a user and former biology professor, who usually insisted on her love for science, asked her if she had ever worked as a sociologist. Constanza replied:

'I studied sociology but please don't think that I believe myself to be a sociologist. I finished my studies and now I do other things'

Ramon: That's great!

Natalia: Do you feel disappointed about what you studied?

Constanza: Yes… unfortunately, sociology is not practical. It's like… you want to do things and you clash against a wall. The stuff about how modern society works is so abstract, it's just palaver, it's useless for me.

Claudio: But I suppose the knowledge has helped you somehow.

Constanza: I mean there's people that believe in sociology, people that think that sociology is the solution for everything… I'm not saying that people shouldn't choose this, its just that my classmates that moved into sociology-related positions are just so far away now, they have no contact with real people anymore.

Claudio (pointing at me): Well, here we have an exception to the rule.

Me: I hope so.

Ramon: That's what we all expect.

[Laughs]

While during the psychology students' situation, I remained in a position of observation, here I was implicated, not only by Claudio, but indirectly by what Constanza was already saying; by her explicit disdain for the identity that I espoused across the meetings. Somehow, her attitude seemed like the right attitude to have in that precise place and moment, but it also made me realise to what extent 'sociology' was a very fragile mark of identification. As a sociologist, I did not hold the functional role of an 'advisor', like the lawyer, even when I was also assisting with the creation of the coffee shop.

Although I was not willing to simply mimic the self-critical stance of Constanza and other professionals, that was a tempting option given the anxieties created by this episode. Claudio's words demonstrated that the group had already invested me with some form of legitimacy. Unlike those bureaucrats working behind four walls, I was participating in activities with real people, like them. I was supposed to be different. Second, it made me confront something that I knew only conceptually: the fact that I could not just dissolve myself in the flux of the conversation; I was there, as an object for the group, and my place was not settled.

Being there, in the heat of the action, meant that I needed to balance the tension in a way that allowed me to remain there (Lichterman, 2017). I wanted to negotiate my own otherness with the group without denying the reasons that had me there in the first place (Parr, 1998). However, after being confronted with the expectations that some members held about me, I realised that maybe I was not being sufficiently clear.


**Vignette 3: Radicalism**

During the final period of fieldwork, I began to think about ways to settle my relationship with the group. They knew that I was leaving; I had only four more meetings with them and I was planning to hold some kind of feedback exercise. At that point, outside of the meetings, I had already received insinuations from Jaime, a professional and one of the founders of the group, that the only thing I should do was to 'bring money from Europe'. I talked this

over with Ramon, who dismissed Jaime's words, but my concern about the group's expectations - and my tensions with Jaime - were growing.

On the 5th of September, I went to the regular Monday meeting. I reminded the group that I was leaving by the end of the month, mentioning my intention to, if they agreed, hold some sort of final session with them. I suggested two options. The first was to have a session about the social sciences, aimed at giving them resources to better engage with students and people conducting research. Ramon had already mentioned the need to address the growing influx of students to the meeting, so I thought that we could have a conversation about that. As a second choice, I proposed the idea of building flowcharts. Just like health services guide their interaction with users through flowcharts, drawing on their own experience, users could also build decision frameworks to deal more effectively with providers. I saw it as a tool for users to visualise the widest possible range of options in view of arbitrary professional decisions.

As I was explaining these options, I felt that some of the participants seemed more interested than others. More precisely, I felt that the way I viewed 'closure' failed to acknowledge how they felt about the fact that I was leaving. Although my intentions to stay in touch with the group were clear, and although I had already talked with Ramon about concrete possibilities of collaboration from the UK, the users in the group expressed something that I could only see as disillusionment, something that I had not anticipated in my technically crafted exit plan.

Somewhat seriously, Ramon said, 'Beside those options, it would be good to hear about what happened to you during this time'. I replied by discussing the impact of the group upon my broader research project; the way the meetings had become a lens to understand the limitations of the mental health system and the potential of users working together, independently of the system.

Natalia, an anthropology student and ally, interrupted me, asking 'Are you a radical now?'. It took me by surprise, and I asked her to explain what she meant. I said that I have always experienced a deep dissatisfaction with the precarious public health system in the country and that my research had always been moved by a concern for the rights and experiences of users, to which she interrupted again, saying 'But I suppose that your ideas have changed a lot, aren't they?'

Although I made copious notes afterwards, this exchange still haunts me. One way to describe the experience would be to say that it felt like a failed rite of passage. My commitment was put to the test, my real intentions

interrogated, and my personal transformation and unity with the group scrutinised. At that point I thought of myself as an ally. A certain energy and sense of connection indeed developed across the fieldwork and increasingly, rather than *about* the group, my field-notes contained ideas and proposals *for* the group.

However, this sudden demand for a public demonstration of commitment and radicality had the paradoxical effect of reminding me that I was there conducting research and that that needed to be clear. I quickly elaborated a clumsy answer that tried to demonstrate the impact of the group on me while simultaneously placing that impact firmly on an analytical level. I had tried not to be pedantic about my profession and my project but, at that point, I felt the need to validate my role. I felt that any confusion about my aims needed to be dispelled. Situated *in* the action, I decided to move away from this intolerable liminality, halfway between observer and collaborator. I chose to be a researcher but, more importantly, I chose to be *perceived* as such.

That day, as usual, the conversation moved into other topics and activities. Still, during the final part, several members expressed their interest in the proposal I had made of a final feedback session. They set up an extraordinary meeting with the sole aim to discuss my findings, on a Friday evening, in the same place they (we) met every Monday. To this meeting came more people than to any other that I had participated in during fieldwork.

## Vignette 4: The final meeting

Something that became clear over the last few weeks of fieldwork was that my relationship with some of the professionals that participated in the group was especially tense. I felt increasingly evaluated in relation to ideals and values that were never explicit, as shown in the prior situations. Talking with some of them outside of the meetings, some of whom I knew from before, I realised that they had carved themselves a place in the group through their harsh stance against other professionals. While service-users were particularly open and welcoming to diverse backgrounds, motivations and contributions to the meetings, some of these professionals were constantly dividing the group's environment into authentic and fake collaborators, worthy and unworthy alliances. Across fieldwork, I relied on my connection and interaction with users, particularly Ramon but, as seen in the prior vignettes, my status as a researcher and the status of social research in general was contested in the group, though not directly.

In the last meeting, I began by discussing some early findings. The role of the State and the distinction between family and user/survivor activism

seemed relevant topics, considering the challenges they were facing at the time, particularly in relation to the organization of the Mad Pride Parade (Montenegro, 2018). Besides this conversation, I proceeded to share a text (see the appendix in page 127) that I had prepared in advance. The text was an attempt to address what I saw as a set of growing tensions and expectations around my role in the group. I was moved by the need to regain a degree of control over these expectations. From the vantage point of the present, I think that such expectations were misplaced and I sense an annoying paternalism across the text. I share it as a testimony of how I saw my situation at that precise point in time, under that precise set of circumstances, considering a mixed scenario of tension with some professionals and trust with most of the rest.

While I read the text, I was interrupted twice by Jaime. Out of the eleven meetings I participated in, he only came to this one. He was irritated by the distinction I made between research and activism. He asked me to provide the exact names and comments made by the authorities that I had interviewed. My unwillingness to reveal personal details about people that explicitly wanted to remain anonymous demonstrated, for him, that my project was not the project of the group and that ultimately I was not part of the group.

As usual, this moment of tension faded into a tumultuous conversation. Everybody wanted to talk. Other professionals discussed their motivations and expressed their own dilemmas in relation to their roles in the group, something that reduced my anxiety. For some reason, this had not been discussed before. A fascinating conversation about the boundaries between professionalism and activism ensued, but it was hard to scribble notes at that point. I was completely engaged, partly because it was my last day with them and partly because I felt able to talk from a position of explicit difference, as a non-user and non-activist conducting social research that, *on that basis,* had something to contribute to the group. More importantly, once the conversation re-started I realised that, for the group, I was just another topic of conversation.

**Conclusions**

*Observing the observational situation.*

Following the call for 'strong reflexivity' (Kuehner et al., 2016) the previous vignettes described my own engagement as a social researcher with a group of mental health service-user activists in Chile. What I experienced as a series of tensions in my attempts to approach and *stay* in the group reveal how the group negotiated its own approachability. The first vignette shows the incongruity between the researchers' attempts to define the group - on the

basis of definitions and principles - and the fluidity of the group. Reacting to this, some members ignored the questions, while others demanded some form of personal connection; a sense of commitment beyond mere curiosity. Vignette 2 demonstrates the ambiguity and limits of identifying as a sociologist; the unsettled place that I had in the group and the legitimising effects of a critical self-distance. Vignette 3 highlights how, in the context of my planned departure from the field, the demand for commitment was increasingly explicit, especially by professionals in the group. Finally, the last vignette is a testimony to how I viewed my situation in the last days of fieldwork.

The description of instances of hesitation and the inclusion of unedited materials produced during fieldwork (See appendix) is an attempt to allow the reader to observe how I came to be observed. Following Devereux, I am guided by the idea that 'not the study of the subject, but that of the observer gives us access to the *essence* of the observational *situation*' (1967, p. XIX. Emphasis in the original).

As stated by Lichterman (1998, p. 403) 'we will understand more about not only social movements but volunteer groups (…) if we attend closely to what it means to be a member'. To put it differently, the fact that my presence was admitted and resisted in the way that it was *says something* about the characteristics of the group. Because of the political drive and their will to differentiate themselves and resist external definitions, sociological observation became suspicious. The threshold of validity that kept me in the group was very dynamic; it shifted over time, and responded to my assertions and expressions of commitment.

In this sense, the *essence* of the observation situation is, fundamentally, a tension between an effort to take a closer look at the actions of group the while negotiating the expectations attached to this proximity. This tension shaped what could be observed, but in ways that were not completely transparent during the process. In Lourau's socio-analytical approach, the act of observation introduces a tension in the field, and this tension is itself a form of analysis, 'an analysis in crisis' (2001, p. 272). This is why tensions should not only be acknowledged - as in most accounts of positionally - but recognised as the basis of a sensitivity and a reflexivity that is always at work during research. However, what more can be said generally about the relationship between activism and academia on the basis of this situation?

*The contingent relationship between activism and academia.*

This section returns to a fundamental question that sits at the heart of this paper: What justifies the participation of social researchers as observers of the activism of users? On a more abstract level, what justifies observation when there is already self-observation? In general, sociologists and other social scientists have immunised themselves against the problem, struggling to maintain a position of neutrality. However, the emergence of hybrid activist-academic communities such as Mad Studies, where users and survivors themselves produce research and create political platforms in academia (Menzies et al., 2013) poses new challenges to the legitimacy of *external* academic observation. The question is still there: what justifies sociological observation when activism is already engaged in the production of knowledge?

Making a critical contribution to this discussion, Spandler and Cresswell have defended an ideal of committed engagement beyond the boundaries of academia and its imperative of neutrality (2013). Through 'reflexive auto-critique' they consider the limits of the academic gaze in relation to the user/survivor movement. On this basis, and following the work of Barker and Cox (2002), they propose the need for 'an effective politico-ethical stance' (Cresswell & Spandler, 2013, p. 142), different to a traditional academic interest. They set out to evaluate the work of scholars interested in user/survivor activism on the basis of the depth of their engagement with the 'lived contradictions' involved in researching social movements.

Because of the nature of my project, these and similar calls are particularly challenging. However, my own 'lived contradictions' somehow differ from these ideal. Based on my experience, more than a politico-ethical stance, I can only try to offer a *retrospective-analytical* stance, even a *testimonial*-stance; one that looks backwards and recognises the accidental nature of encounters and dis-encounters across qualitative, field-based research projects. Such stances do not present themselves as right or wrong but as a contingent outcome of the situations experienced in the field and, to an important degree, as an outcome of the encounter itself, of the unsettled negotiation of roles between the researcher and activists.

In this sense, what Spandler and Cresswell define as 'depth of engagement' needs to be examined. In a context of emergence and self-differentiation, visions of transformation and horizons of action are *in the making*. Aligning one's stance with that of the research participants - or with an abstract, effective stance - would prevent the researcher from perceiving the diversity of political and ethical orientations that take part in activist spaces. Furthermore, if 'engagement' is a condition of possibility of valid observation, then one could ask about the conditions of possibility of engagement itself. In my view, that which makes engagement valid is a contingent outcome of

engagement. Validity, in this sense, is not achievable *before contact.* Everything starts with contact. Sometimes, a process of intense political alliance and connection between researchers and activists will begin. Other times, a series of tensions, miscommunications and doubts will ensue. Yet other times, an oscillation between connection and tension, commitments and doubts will take place. What it is important in the context of this paper is to recognise the analytical value that each potential sequence of actions holds, beyond any preconceived sense of commitment. Metaphorically speaking, accidents reveal the texture of the field itself.


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**Appendix**

Letter to Libre Mente
(23/11/2015).

*Sociologists do research. We hardly know how to do other things. As social scientists, we relate to people and processes through curiosity. We aren't moved by any specific power dispute, we don't believe ourselves better than other people and unless our curiosity expires, we don't want to lead other people. Power disputes, groups formation, values and social struggles are part of what we want to understand. We want to contribute with what we know best, with what we love: social research. That's what we bring to the struggle.*

*We express support by choosing what to research, where to turn on our recording devices, what to observe. Users, ex-users and survivors have been left out of the creation of that thing called 'mental health'. And that's what I, as a social scientist, have tried to understand at this stage.*

*I've chosen the social sciences because I wanted to understand society. Within society, I've chosen mental health as the object of research, because I believe that Mental Health doesn't have social 'aspects': It is entirely social, it tells stuff about society. And I've been doing that for almost 7 years. I've chosen to use ethnography and that means immersing yourself in the situation.*

*Working with you and other user groups, where there are other professionals and different collaborators, something that I want to suggest to you is to think about your goals as a user-led organisation. If you are here it is because your interests go beyond each individual interest. The group is based on the idea of transforming society and, therefore, no professional pressure, no political tendency, and no specific power dispute should distort what you, as people who have experienced psychiatric abuse, want and dream for the group.*

*What I've seen in many places is how professionals are actively taking the flag of the users' struggle. They do it, lots of times, following personal goals. I've talked about this with the other groups I'm working with. We, professionals, can collaborate but we don't own this fight. We are just that, professionals, and only if we get that difference right we can start to think and act more democratically and horizontally within the field of mental health.*

*To adopt a battle flag means several different things. It makes us win extra-curricular points, it pushes us through dynamics of prestige, it gives us power. Let's not forget this. Any field, including the mental health field, and including the field constituted by users/survivors and their demands and actions, implies the development of forms of influence and power. Reputational power, political power, social power. Only by examining this will we be able to collaborate through our differences, and not in spite of them. We don't need to be 'the same' to work together. Much to the contrary, communication and real collaboration are only possible once differences have been recognised and accepted. Only if we accept these differences can we control the messianic, personalist and paternalistic tendencies that we find in many professionals engaged with activism.*

*The most transcendental and critical battle is your battle, the battle of those who have gone through psychiatry and have been abused by it. We, the rest, need to accept that. Even when we support this struggle, we can't own it, we can't be its representatives, we can't interfere with it. We, the rest, work as collaborators, through what we do best. As professionals, we must avoid any invitation to represent the voice of users. And to do this we have to be professionals, in the best sense of the word, people who have chosen something to do, and that do it well.*

*Finally, when the point is to create social changes and create consciousness among as many people as possible, a key activity is, precisely, to engage in relations with many people and with many interests. The relation that the group develops with these 'others' can't be dominated by suspicion or judgment. One fundamental aspect that makes this group unique is its openness, open meetings where anyone can come to know, to look, to work, or simply out of curiosity. But this open nature is very fragile, it needs care and attention. Therefore, Manichaeism and fundamentalism need to be resisted, those self-assured positions that separate the bad from the good, the authentic from the inauthentic.*

*The group doesn't need leaders to establish who are the good and the bad guys, pre-selecting who to work with and who to avoid. That would be another form of paternalism. We're all entangled in multiple positions, stories and interests, joined by beliefs, practices, and space. Even those groups that seem more homogenous are filled with tensions and differences, differences through which you, as a group, can make more differences. In this way, we can avoid the exclusion and demonization of the different; precisely what this group is all about.*

# CHAPTER 3: CONCLUSIONS

This section provides an integrated interpretation of the findings of the four papers, identifying their contribution to the study of service-user involvement and participation in the mental health field. In the first part, I return to the original research questions to provide a concise answer that links the findings of each paper. A number of lessons learned in the process of answering these questions are then presented and discussed in the context of key debates in the literature regarding service-user involvement and activist practices.

## 3.1 Addressing the research questions

The first overarching set of research questions was:

*What are the processes that underlie the way the Chilean mental health system has come to observe and approach the reality of service-user organisations and the meaning of service-user involvement? How has the image of user groups changed over time and in relation to which transformations in the mental health system?*

Paper 1 demonstrated how users come to represent different ideas at different points in time and in relation to different demands and expectations rooted in the specific transformations of the mental health system in Chile. User involvement makes sense and becomes relevant not because of its intrinsic value but because of the strategic role that it plays in relation to the challenges faced by the mental health system and its quest for financial stability, legal legitimacy and relevance vis-à-vis many other health priorities in the country.

The main finding in this sense is that participation is a temporal process. Only by approaching it as such it is possible to appreciate how policy decisions have created a minimal set of conditions for users to develop their own organising efforts over time.

Paper 2 brings this focus on process to bear on a specific initiative of community-engagement. The initiative involved a sequence of policy actions that produced a fragile framework of engagement with user groups. This framework created new problems and further adaptations became necessary, demonstrating the administrative complexity implied in a process of contact with the community.

The contribution of these papers is discussed in the context of contemporary debates in the following section, but it is important to state that they problematise the technical view that participation can be implemented and assessed in a unilateral way. Participation involves policy decisions, but it is not *a* decision. It responds to contingent scenarios and it introduces unexpected dynamics that create further complexity. The papers expanded the scope of what to look at when examining participation (Cefaï, Carrel, Talpin, Eliasoph, & Lichterman, 2012), to include the policy drives that make participation relevant, the fragile ways in which participatory ideals are translated into practice, the unexpected effects that participatory initiatives create in health settings, the way user groups take advantage of these openings and the permanent risks that further policy transformations place on the interaction between health organisations and local communities.

The second set of questions addressed by the thesis was:

*How do autonomous user groups organise and define themselves vis-à-vis the observation and expectations of mental health systems? How do they distinguish themselves from the image created by these systems?*

Paper 3 demonstrated that there are two levels in the response to this question. Activists reacted against what they saw as illegitimate and violent mental health practices, discourses and institutions. However, especially for users, the main focus of attention and care was the group itself, its sustainability over time and its integrity in the face of external interests and agendas. The main goal for users was the creation of a realm of reciprocity and meaning that could thrive outside of the reifying gaze of the mental health system.

This will to self-differentiation, which is referred to in the papers as a politics of incommensurability, follows the structure of what Rancière identifies as the defining feature of a political disagreement: not a confrontation between positions about a set of topics - for example about psychiatric diagnosis, the effects of medication, irreversible treatments and coercion, etc. - but a more fundamental disagreement about who is entitled to take part in that confrontation (1999). The main object of the dispute is the ability of users themselves to participate in the discussion. With this in mind, what seemed to be mere practical decisions and deliberations within the group are all aspects or stages of a political intervention, one by which they came to recognise themselves as already part of the community of those who actually have a voice and can speak about themselves (Rancière, 2010).

Finally, Paper 4 provided a reflexive account of how the politics of incommensurability espoused by user groups was expressed in the process of negotiation of my own presence and academic interests within the group, and the presence and interests of social researchers in general. Reflective vignettes from the field showed at the micro level how academic curiosity, values and ideas clashed against the fluidity and diversity of the group. More importantly, they demonstrated how the group counter-interrogated, demanding a personal connection and/or a degree of commitment as a condition of possibility of knowledge *about* the group. The contribution of the paper is to frame reflexivity as a key tool in exploring the politics of knowledge and membership that shape service-user activist spaces, and to underscore how this politics challenges the interests and goals of social researchers.

The scenario that inspired my desire to approach this topic, recounted in the introduction, pointed to the need to understand both the collective actions of service-user groups and the reasons why they have been *seen as invisible* by mental health systems. In the following section, I summarise the lessons learned in this process and the implications of these results in relation a number of debates in the literature about service-user participation and activism.

## 3.2 Lessons of this thesis in relation to contemporary debates about participation and activism in the mental health field

### 3.2.1 Real and superficial participation

Part of the critical literature on participatory practices and discourses relies on and reproduces an explicit or implicit normative separation between 'superficial' and 'deep' participation (Roark, 2014). This underlies other distinctions, such as the one between 'consumerist' and 'democratic' participation (Beresford, 2002) and, more recently, the distinction between 'claimed' and 'invited' spaces (Cornwall, 2004, 2008). Invited spaces are the ones that policy makers, authorities and/or professionals create for users to participate. On the other hand, claimed spaces are the instances of engagement and collective action produced and/or 'conquered' by service-users autonomously.

Papers 1 and 2 presented cases of 'invited' spaces. The creation of ANUSSAM responded to a requirement of the Mental Health Department of the Ministry of Health. The 'Community Mental Health Network', described in Paper 2, was a unilateral design whose aim was to become the official form of contact between a health service and local user groups.

Nevertheless, the adoption of a constructivist approach - such as social systems theory - problematises the distinction between superficial/invited and deep/claimed spaces. The theory adds an epistemological dimension to the scepticism about invited spaces: Systems do not only own and control invited spaces, but cannot hear what users have to say unless users adapt their actions and claims to the internal configuration of priorities and forms of truth of the system. In other words, the relevance of users' collective actions and concerns responds to the internal dynamics of the system. Invited spaces are still closed spaces, guided by the selectivity that defines the boundaries between the mental health system and its *outside*.

The case of the AUGE reform and the sudden delegitimisation of user voices exemplify this situation (Paper 1). Yet, the same example reveals something else: in accepting the process of reform the mental health system consolidated its own position within the public and private health sector. That means that the reductive form used by the system to observe and approach the reality of user groups is itself the result of broader policy pressures upon the mental health system. In this sense, while recognising the defining characteristics of invited spaces - such as narrowness and superficiality - these characteristics respond to the fragile place from where the *invitation* comes. In the same way, Paper 2 traced the administrative conditions of possibility of participatory efforts, revealing that, despite the efforts to solve the deficit of legitimacy and internal democracy of the network, the resulting framework of engagement with communities was still threatened by subsequent administrative requirements and by simultaneous participatory attempts.

These findings underscored the fragile conditions and the fugacity of participatory projects. These aspects are made conceptually irrelevant when the emphasis is placed on evaluating to what extent participatory initiatives are real or superficial.

Papers 3 and 4, on the other hand, described the ways in which these users created a space of their own, separated from the type of group that the mental health system had relied upon in order to advance its policy agenda since deinstitutionalisation, including family groups, NGOs, scientific organisations, academia, etc. However, although it is possible to classify their actions as more 'authentic' or as a proper 'claimed' space, the most relevant contribution of the thesis is to demonstrate how user groups classify other groups and agents - even myself - across normative parameters. Normative distinctions have a social life of their own, creating concrete exclusions and solidarities.

As stated by Luhmann, 'society (…) is neither good nor bad but the condition that something can be so characterised' (1991, pp. 89–90). This means that the sociological study of participation in health and other fields should include within its scope of enquiry the study of how certain actions, agents and initiatives come to be perceived as real or superficial, claimed or invited; tracing, case by case, the forms that these dichotomies adopt, the way in which they are used and the effects that they generate.

### 3.2.2 The discontinuity of participation

Cherry Arnstein's 'Ladder of participation' has organised for many years the way in which participation is understood and promoted in policy discourse (Arnstein, 1969; Bacqué & Gauthier, 2017). Its influence can be seen in subsequent, more sophisticated metaphorical efforts, including the distinction between claimed and invited spaces (Cornwall, 2004). Still, the most enduring feature of the ladder are not the steps that it maps but its ability to represent participation as a scale or a continuum going from the superficial - or tokenistic participation - to the 'deep', citizen-led control of public services. In line with the problematisation of normative parameters in general, this thesis has found that discontinuity is a critical aspect of how participation and participatory practices operate in concrete settings. There are several dimension of this discontinuity.

First, participatory impulses and initiatives wax and wane according to specific political and economic forces affecting the health system. Participatory initiatives appear and evolve but are always at risk of irrelevance, as Paper 2 demonstrated. This irrelevance has many sources. It can be related to shifting policy orientations determining the kind of funding and support provided to participatory projects, or to emergent policy values affecting, in turn, the value that participation has at the local level. Alternatively, it can be related to new 'foundations' for policy-making, for example the shift towards evidence-based policies that, as seen in Paper 1, inadvertently marginalised the importance of user voices in the definition of policy.

There is another dimension to this discontinuity. Each of these shifts produces conditions for user groups to develop simultaneous processes that, in many cases, are minimised by the rational sequence recounted by policy makers (Paper 1). Every invitation accepted by users is not just a superficial gesture; it creates conditions for further organising activity. The history of ANUSSAM clearly points to this. While mental health authorities found their own ways to justify the poor engagement with user groups after 2000, ANUSSAM members had a very different view. For them, this was the starting

point of a difficult but rewarding process of maturation that could not have taken place without those initial invitations. In this sense, actions such as the creation of ANUSSAM cannot be placed neatly within a continuum of participation. More precisely, every action in a process of participation cannot be seen as a singular point, but as the opening of several lines of development that cannot be mapped into a single continuum.

Finally, the insistence of Agrupación Libre Mente (ALM), described in Paper 3, on moving away from any sort of engagement with authorities or professionals and to distance itself from the kind of public with which the mental health system had worked over the years, challenges a direct categorisation within a continuum of participation. ALM could be situated at the extreme of 'citizen control' suggested by Arnstein or as a case of a 'claimed space' (Cornwall, 2004). However, the politics of differentiation that they embraced somehow break the continuum. Between ANUSSAM and ALM, it is very hard to recognise a unitary plane of action. They represent two participatory 'lifeforms', distinct ways of being with different sets of goals, political motives, forms of action and visions of the State, madness and difference. In this sense, instead of a continuum in which groups and participatory projects could be classified, the lesson of this thesis is that participatory experiences and these groups and projects should be approached as multi-layered and dynamic ecologies of participation (Chilvers, Pallett, & Hargreaves, 2018).

### 3.2.3 The impact of participation

The main goal of papers 1 and 2 was to understand how mental health systems and policies conditioned what was expected from service-user groups and the kinds of spaces that were created for them to participate. Papers 3 and 4, on the other hand, focus on how service-user groups react to these expectations, producing independent and incommensurable forms of collective action. What is missing is a consideration of the kind of impact that activism and participatory practices have on mental health systems. While user groups aimed their actions to be indifferent in relation to the mental health system and its goals, I want to contend that, precisely because of this, they do have an impact, but one that does not map itself clearly onto how impact is usually understood in the field (Omeni, Barnes, MacDonald, Crawford, & Rose, 2014).

To develop this point, it's important to return to the story recounted in the introduction. In 2015, immediately after coming back to Chile for fieldwork, I interviewed a member of the team in charge of the data collection process that led to the WHO AIMS 2014 report, and to the statement that 'a low presence

and a poor level of organisation of the mental health users and family members associations is still observed' (WHO & Ministerio de Salud, 2014, p. 11). I wanted to know what kind of data they collected and how they had arrived at this conclusion. He told me that, in order to measure the existence of users groups, they first tried to assemble a valid list of every single user organisation in the country. They searched for the list across ministries (health and disability, more specifically), only to find partial or outdated versions. They ended up with a mix of incompatible registers that different institutions produced in response to the requirement.

To somehow arrive at a better estimate, the team decided to call the mental health referents of each one of the 23 local health trusts in the country, enquiring about the user groups that they knew or had worked with. However, these professionals could not differentiate a user organisation from the group-based therapeutic activities that they coordinated.

> 'They would confuse proper user organisations with group interventions conducted by professionals (…) when we asked them 'could you name the user organisations that you know' they described the group interventions that they coordinated, the workshops and group activities with the users of their centres'.

The inability of professionals to differentiate the independent actions *of* users from their own actions *with* users is revealing. For professionals, user groups could only be conceived and perceived as an outcome of their own, professional action. In a similar way, Paper 2 showed how the interests and internal organisation of local groups was a primary concern for professionals and how they assumed the role of safeguarding the 'meaning' of participation and community-based work. What this reveals is that professionals not only *ignore* the existence of independent local groups, but, more precisely, they do not have a concept that could make them differentiate what they do from what users could do. They ignore their own ignorance.

How can this logic be broken? The answer to this question is precisely the answer to the question about the impact of user groups. Based on our findings, when groups such as ALM reject the invitation to work with the mental health system and instead reclaim madness and turn it into a public manifestation - via the Mad Pride Parade - they not only *dispute* the definition of what a service-user group is or should be. More precisely, they *create* the conditions for something to be perceived. They make an aesthetic intervention, if, together with Rancière, we understand aesthetics as 'the system of a priori forms determining what presents itself to sense experience' (2013, p. 8). Their impact is, then, political, if by politics we understand the reconfiguration of 'the distribution of the sensible which defines the common of a community, to introduce into it *new subjects and objects*, to render visible

what had not been, and to make heard as speakers those who had been perceived as mere noisy animals' (Rancière, 2009, p. 25).

This research project captured the moment in which the disagreement is not only about the characteristics of services, the lack of resources for mental health or even the stigma attached to mental illness. The dispute is more fundamental, and concerns the very idea of what service users are and what they can do together (Contandriopoulos, 2004). When they affirm an incommensurable distance between them and the mental health system, they create the ground for professionals to recognise the difference between what they do and what users do, publicly, loudly, in the streets. On the basis of this difference, professionals can either engage or they can decide to ignore - but this will be a decision based on the existence of a difference.

### 3.2.4 Participation and representation

Closely connected with the notion of impact, the modern concept of representation points to the ability of an individual or group of individuals to act in the name of another. In more abstract terms, and considering its etymology, representation involves 'the making present in some sense of something which is nevertheless not present literally or in fact' (Pitkin, 1967, pp. 8–9). Many participatory projects respond to the need to make users present in decisions over policy. But the relationship between the representative and the represented (Martin, 2008), the ways in which representatives are selected (El Enany, Currie, & Lockett, 2013), the kind of people and issues that can or cannot be represented (Maguire & Britten, 2017) and they ways in which users themselves embody and signal their *representativity* (Voronka, 2017a) are all highly contentious issues in the literature.

To contribute to these discussions, this thesis frames representation as a time-based bureaucratic process. As detailed in Paper 1, during the nineties, and in the context of deinstitutionalisation, family groups became relevant and many of them were created. For the authorities, representativeness was related to the ability of a certain group to know and be connected with a broader universe of groups. Eventually - and naturally - the mental health department questioned the extent of that connection but, as recognised by authorities in the interviews, once the representative was constituted it is not required for him to make *something else* present to the space of decisions.

ANUSSAM arrived at a position of representation not through an independent process of engagement but thanks to their relationship with CORFAUSAM, the group that the mental health system defined as

*representing* the universe of family/caregiver organisations in the country (Paper 1). In this sense, a time-based, processual view of representation puts the emphasis on the series of contingent matches between institutional requirements for *presence* and community-based groups interested in re-present.

Papers 3 and 4, on the other hand, demonstrate how user groups experimented with forms of political engagement that explicitly avoided representation. For ALM, the main concern was the group itself, the relationships formed within it and its ability to become a space of self-expression. They carefully avoided the adoption of legal forms and internal differentiations that could introduce the need for representation. When they accepted invitations to talk about madness or psychiatry, they rotated the role of spokesperson through the group. They saw these instances as opportunities to learn and share their views, but in a very personal way and without claiming the representation of a wider constituency.

While traditionally representation assumes the existence of one previously constituted agent or group that is re-presented in the context of another group or space, the 'mad' identity claimed by users does not fit into a scheme of representation. In line with what was said about 'impact', what makes the actions of service-users and ex-users political is not a regime of delegation and authorisation, but a capacity to affect the conditions of possibility of representation itself, what Rancière calls the distribution of the sensible (Lievens, 2014; Rancière, 1999). Actions like the Mad Pride Parade were not attempts to make their concerns visible and audible to this or that institution but, more fundamentally, they were interventions into what can be perceived and, therefore, what can be represented.

To summarise, this thesis contributes two elements to the debate about representation in the context of participation: First, treated as a process, representation is the outcome of a match between a demand for a representative and the contingent proximity and interest of one or more groups in relation to that demand. Second, representation is not a central concern or a necessary condition for emergent groups to act politically.

### 3.2.5 Experience and evidence

The notion of experience and, more precisely 'lived experience', plays a critical role in the literature about service-user involvement and activism. Most projects of involvement are based on the idea that users have a unique and irreplaceable knowledge based on their experiences at the receiving end of services, a knowledge that can be used to improve those services (Eide,

Josephsson, & Vik, 2017; Kogstad, Ekeland, & Hummelvoll, 2014; Lester & Tritter, 2005).

Nevertheless, increasingly the relationship between experience and expertise is being debated (McKevitt, 2013; Meriluoto, 2017). Jones and Kelly argue that the position from which an experience can be conveyed is not unitary; it changes in response to the practical situations taking place to an individual or a group (2015). Meanwhile, Voronka argues that the notion and value of 'lived experience' is dependent on formalised policy expectations about the role and contribution of users (2017b). Specific aspects of a life trajectory are articulated and made meaningful as 'experience' in the context of negotiations and demands attached to institutionalised definitions (Ibid).

The findings of this project support and expand this line of analysis, through a systemic framework that reveals how different systems deal with user experiences in different ways. As shown in Paper 1, valid scientific evidence became the main criterion for policy decisions in Chile in the early 2000s, leaving users out of the conversation. On the contrary, the legal system, whose role in the process of deinstitutionalisation was fundamental, simultaneously gave specific value to the experience of users, demanding their participation in the decision-making process behind the application of coercive measures.

The way experience is variably valued and mobilised can also be observed in the case of ALM. As Paper 3 demonstrated, ALM decided not to adopt the form that would have made them visible for the legal system and the mental health system. Instead, they focused their energies on organising a public manifestation that could be, in turn, *experienced* by other people who had nothing to do with the mental health system. The coffee shop project had the same ambition: to make other people take part in the kind of world that they wanted to create.

In many approaches to involvement, 'experience' is usually sought after as a way to improve services (Kogstad et al., 2014; Lester & Tritter, 2005). The premise is that experience is, generally, negative. Only because of that it makes sense to learn from users' experiences. Groups such as ALM had many bad experiences with services but, collectively, they transformed them into experiences of difference that could be shared with the wider public, without the intermediation of health systems. The lesson of this thesis is that users are not containers of more or less useful experiences but creators of worlds of difference that can be *experienced* by others.

In summary, this thesis contributes to debates about experience by revealing how the experience of service users is differently valued by different

systems and how, on the other hand, autonomous user groups use their experience creatively and expressively to affect others, beyond institutional mediations.


### 3.3 Concluding remarks: Global ambitions, local politics

The global call for users involvement launched by the WHO and supported by other international bodies has been followed by different attempts to assess user participation, within and across countries (Wallcraft et al., 2011; World Health Organization, 2013). These evaluations see the role of service users as continuous with mental health systems, with no differentiation between family/caregiver and user groups. Under the general principle of 'scaling up'' services (Semrau et al., 2015) and consonant with the ambitions of contemporary global mental health (Eaton et al., 2011; Patel, Minas, Cohen, & Prince, 2014), these studies are shaping how participation is designed and verified in different parts of the world. On the basis of our findings, several concerns can be raised about these ambitions.

Systems theory notion that observation is an operation of a system *within* itself is clearly well suited to understand users' invisibility, as has been pointed out across the thesis. When policy systems observe their exteriority in search for information about, for example, user groups, they do so through themselves, through the distinctions upon which they are built as systems. Following James Scott's notion of state projects of legibility and simplification (1998), in order to see, policy systems first need to map themselves onto what they want to see.

In this sense, the work of global policy calls and information requirements is paradoxical. On the one hand, the WHO AIMS (and other tools such as the QualityRights) introduces an abstract notion of 'service-user involvement' and its importance. At the national level, this creates a moment of interrogation and searching: 'are users organised?', 'where are the organisations?', 'what do they want?' and, especially, 'how do we reach them?'. Global calls and assessment tools are able to introduce questions and conversations to the local level. However, and herein lies the paradox, due to the narrow response categories -justified on the grounds of comparability - and the strict timeframes that they demand, they end up reproducing the common sense idea that users are disorganised and weak. Blind-spots of observation are translated as a weaknesses and failures of user groups.

There is another aspect to the problem. Agents such as the WHO have a privileged interaction with national health systems. Even when introducing new vocabularies and 'progressive' expectations (such as service-user

involvement or recovery-based service-models), these agents produce information about countries via national-level self-assessments. As this thesis has shown, there are autonomous user groups that organise themselves outside - and against- the reach of mental health systems. What can be assessed in this scenario? In the context of international assessment tools that, in many cases, are used to signal national progress to the international community, can the existence of opposing voices be recognised?

It is tempting to use the findings of this thesis as grounds to make policy suggestions, recommending ways to overcome the insubstantial attempts of institutions and professionals to *do* participation and helping them to, somehow, increase their sensitivity towards the autonomous presence, actions and demands of users. But, above all the others, the main personal and analytic lesson of this thesis is that user groups actively and strategically resist these attempts, focusing instead on producing messages, symbols and experiences that situate themselves in front of *others* in their own terms. This unsettles in equal terms the participatory goals of policy and the reifying ambitions of the social sciences.


## 3.4 Limitations of this study and ways forward

As stated in the introductory sections of each of the papers, users' organising actions and mental health participatory initiatives are a recent phenomenon in Chile and Latin America. This thesis is an initial attempt to explore these emergent processes and, therefore, there are several limitations that I would like to discuss.

Time was a key limitation. I spent three months in Chile for fieldwork. There were several activities before and after this period that could have contributed to the investigation. Furthermore, extended time with user groups could have given me a more nuanced and comprehensive view of their maturation and transformation, of their engagement with other activist groups outside of the field of mental health and of their interaction with professionals outside activism, among other things.

Although through many informal and formal conversations I got to know the lives of a small group of users in ALM, I could not explore their trajectories and the more detailed narratives that they used to make sense of the transition from psychiatric patient to mental health activist. Narrative approaches are very prominent in studies of empowerment and participation in mental health (Basset & Stickley, 2010; Cohen, 2008) and this could have been the case for this study. My wish is to apply this kind of approach to a second study that will also trace the changes occurred to the organisation over time.

This study was focused on Chile, but service-user organisations also exist in other countries in the region, notably in Brazil and Argentina. A comparative approach to the goals, organising strategies and evolution of these groups within the region and/or beyond would be valuable, particularly because it could show the kind of contextual elements (policy-background, social, cultural and political factors) that shape the ways in which users organise themselves. This thesis provides some broad parameters to articulate a comparative approach.

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# ANNEX 1: METHODS

The papers included in this thesis have their own methodological section. This section presents relevant information that is not provided in each paper, detailed in the following list:

1. Overview of methods used in the papers
2. Paper 1
   a. List of interviews
   b. Documents
   c. Topic guideline for interviews
   d. Coding framework
3. Paper 2
   a. List of interviews
   b. Documents
   c. Topic guidelines for interviews
   d. Coding framework
4. Paper 3
   a. List of sites and dates of participant observation

As indicated before, paper 4 is a reflexive account of how my presence was accepted and resisted in the field. It is based on the same fieldwork process and dataset than paper 3.

## 1. Overview of methods used in the papers

| Paper | Title | Main technique | Secondary technique | Approach | Analysis |
|---|---|---|---|---|---|
| 1 | Historicising involvement: the visibility of user groups in the modernisation of the Chilean Mental Health System | Interviews | Analysis of documents | Oral History | Process oriented thematic analysis |
| 2 | "Making contact". Tentative engagements between institutions and communities in Chile's mental health field. | Interviews | Participant Observation | | Process oriented thematic analysis |

| 3 | Beyond Participation: Politics, Incommensurability and the Emergence of Mental Health Service Users' Activism in Chile | Interviews | Participant Observation | Focused ethnography | Ethnographic analysis |
|---|---|---|---|---|---|
| 4 | "Are you a radical now?". Reflecting on the situation of social research(ers) in the context of service-user activism in Mental Health. | Participant Obs. | | Reflexive vignette | Reflexive vignette |

## 2. Paper 1

### A. List of interviews

| Date of the interview | Pseudonym | Position / Group |
|---|---|---|
| 29/07/2015 | Sandra Roman | Current Mental Health Authority |
| 31/07/2015 | Nicolas Galiani | Former Mental Health Authority |
| 04/08/2015 | Javiera Reyes | Former Mental Health Authority |
| 05/08/2015 | Gonzalo Poblete | User Organisation |
| 07/08/2015 | Ramón Bravo | User Organisation |
| 12/08/2015 | Valeria Canales | User Organisation |
| 20/08/2015 | Alonso Jimenez | Current Mental Health Authority |
| 20/08/2015 | Lidia Hernandez | Current Mental Health Authority |
| 26/08/2015 | Julio Cáceres | Former Mental Health Authority |
| 27/08/2015 | Samuel Robles | Family Organisation |
| 28/08/2015 | Hector Barra | User Organisation |
| 28/08/2015 | Daniela Perez | User Organisation |
| 08/10/2015 | Fabio Diaz | Current Mental Health Authority |
| 08/10/2015 | Fernando Flores | Former Mental Health Authority |
| 09/10/2015 | José Salas | User Organisation |
| 18/11/2015 | Sara Castro | Family Organisation |
| 18/11/2015 | Manuela Valenzuela | Family Organisation |

*B. Context setting documents.*

| Year | Name | Author |
|------|------|--------|
| 1982 | Normas terapéuticas. | Hospital Psiquiátrico de Santiago |
| 1990 | Plan Nacional de Salud Mental y Psiquiatría | Ministerio de Salud |
| 1990 | Manual de técnicas para grupos de personas con trastornos emocionales | Ministerio de Salud |
| 1991 | Memoria Centros Comunitarios Salud Mental | Ministerio de Salud |
| 1992 | Manual gestión participativa y salud mental | Ministerio de Salud |
| 1993 | Políticas y Plan Nacional de Salud Mental | Ministerio de Salud |
| 1993 | Plan de Transtornos Emocionales | Ministerio de Salud |
| 1994 | Memoria Centros Comunitarios Salud Mental | Ministerio de Salud |
| 1994 | Salud y derechos humanos | Ministerio de Salud |
| 1995 | Normas básicas para la acreditación de servicios de internación psiquiátrica. | Ministerio de Salud |
| 1995 | Programa de salud mental y asistencia psiquiátrica 1994 - 1995 | Servicio de Salud Metropolitano Norte |
| 1997 | Salud mental en la escuela | Ministerio de Salud |
| 1998 | Diagnóstico y tratamiento de la depresión en nivel primario de atención | Ministerio de Salud |
| 1999 | Las enfermedades mentales en Chile | Ministerio de Salud |
| 1999 | Norma técnica organización de una red de salud mental | Ministerio de Salud |
| 1999 | Red de salud mental y social | Servicio de Salud Metropolitano Occidente |
| 1999 | Recomendación sobre la Promoción y Protección de los Derechos de las Personas con Discapacidad Mental | Comisión Interamericana de Derechos Humanos |
| 2000 | Guía planificación de diseño unidad hospitalización de corta estadía en psiquiatría | Ministerio de Salud |
| 2000 | Norma técnica terapia electroconvulsivante modificada | Ministerio de Salud |
| 2000 | Norma técnica hogares protegidos | Ministerio de Salud |
| 2000 | Norma técnica uso clínico de clozapina | Ministerio de Salud |
| 2000 | Plan nacional de salud mental y psiquiatría | Ministerio de Salud |
| 2000 | 2000 Reglamento de Internación (570) | Ministerio de Salud |
| 2000 | Estudio de hogares protegidos | Ministerio de Salud |
| 2000 | Orientaciones técnicas tratamiento y rehabilitación personas afectadas esquizofrenia | Ministerio de Salud |
| 2002 | Orientaciones técnicas para desarrollo clubes integración social | Ministerio de Salud |
| 2002 | Orientaciones técnicas para hospitales de día | Ministerio de Salud |
| 2003 | Norma General de Contención en Psiquiatría | Ministerio de Salud |

| 2003 | Plan de Mejora de Calidad en Salud Mental Departamento de Salud Mental Ministerio de Salud, Chile 2003 | Ministerio de Salud |
|---|---|---|
| 2003 | Programa Académico Referencial para la Formación de Especialistas en Psiquiatría | Ministerio de Salud |
| 2005 | Inclusión social, discapacidad y políticas públicas | Ministerio de Educación |
| 2005 | Enfermedad mental, derechos humanos y exclusión social | Ministerio de Salud |
| 2005 | Guía clínica para detección y tratamiento temprano de alcohol y otras sustancias psicoactivas | Ministerio de Salud |
| 2005 | Guía GES Esquizofrenia | Ministerio de Salud |
| 2005 | Norma de esterilización quirúrgica en personas con enfermedad mental | Ministerio de Salud |
| 2005 | Enfermería en salud mental comunitaria | Ministerio de Salud |
| 2006 | Instrumentos para la evaluación de atención salud mental red asistencial | Ministerio de Salud |
| 2006 | Guía Clínica GES Depresión | Ministerio de Salud |
| 2006 | Memoria comisión de protección de derechos humanos | Ministerio de Salud |
| 2006 | Norma técnica tratamiento adolescentes infractores de ley, alcohol y drogas | Ministerio de Salud |
| 2006 | Norma técnica residencias protegidas | Ministerio de Salud |
| 2006 | Norma Técnica Rehabilitación psicosocial | Ministerio de Salud |
| 2006 | WHO Assessment Instrument for Mental Health Systems, Chile | Ministerio de Salud |
| 2007 | Guía clínica GES alcohol y drogas en menores de 20 años | Ministerio de Salud |
| 2007 | Manual para el proceso de evaluación de la calidad de atención en salud mental | Ministerio de Salud |
| 2007 | Orientaciones técnicas atención de niños, niñas y adolecentes con trastornos mentales | Ministerio de Salud |
| 2007 | Orientaciones técnicas tratamiento del consumo problemático de alcohol y drogas | Ministerio de Salud |
| 2007 | Normas Uniformes sobre la Igualdad de Oportunidades para las Personas con Discapacidad | Organización Mundial de la Salud |
| 2008 | Decreto 201 Promulga Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad y su Protocolo Facultativo | Ministerio de Relaciones Exteriores |
| 2008 | Orientaciones técnicas centros de corta y mediana estadía | Ministerio de Salud |
| 2008 | Estudio Sobre Legislación Chilena y Salud Mental | Ministerio de Salud |
| 2008 | Manual de desarrollo psicosocial | Ministerio de Salud |
| 2008 | Norma técnica centro salud mental comunitario | Ministerio de Salud |
| 2008 | Visita domiciliaria integral en salud mental | Ministerio de Salud |

| 2009 | Orientaciones técnicas Atención Adolescentes con Problemas de Salud Mental | Ministerio de Salud |
|------|----------------------------------------------------------------------------|---------------------|
| 2009 | Guía GES esquizofrenia 2009 | Ministerio de Salud |

As indicated in paper 1, ANUSSAM provided 26 digital documents including funding proposals, reports of activities, and administrative and legal documents related to their legal consolidation. These documents are of internal use so they are not presented in a table here.

*C. Topic guides for interviews*

<u>Questions for Former Policy Makers.</u>

| | |
|---|---|
| 1. | First, I would like you to think and try to position yourself in the early process of reform of the mental health field in Chile. What was your specific position in this process? |
| 2. | During the early 90s, thinking about the process of reorganisation of the Chilean mental health system, what was, in general, the vision around the role of civil society in this process? |
| 3. | Was the role of users and users organisations being discussed or considered? Was it something important? Why? |
| 4. | What do you think were the main drivers behind the idea that users should participate in the process? |
| 5. | Considering the growing call for users' involvement in MH policy from the WHO and other international actors, do you recognise some form of international or external influence in the way in which users were conceived and approached on this early stage? For example, coming from the Caracas Declaration? |
| 6. | What kind of concrete actions or decisions were made around the role or the involvement or recognition of users voice? |
| | a. Plans |
| | b. Measurement, assessment, evaluation mechanisms |
| | c. Encounters or other forms of engagement |
| 7. | How do you personally evaluate these actions considering your original views about the role of users? |
| 8. | Considering the early visions around the participation of user groups, what are the main changes that you have seen over time? |
| 9. | What are the causes or explanations of this changes? |
| 10. | Is there any decision or lack of decision that you regret, or that you would make differently in relation to the involvement of users? |

## Questions for current professionals and policymakers

| |
|---|
| 1. First I would like to know more about your role as _____ in this unit. |
| 2. What are the main policy challenges and processes faced by the MH unit, both from your position and as a whole? |
| 3. According to the latest WHO MH plan, users and their organisations have a role to play in policy. Do you agree with the idea that users organisations should be involved in policy? Why? |
| 4. Are there any current projects or concrete actions related to involving users in policy processes and or working with users organisations? |
|    a. Plans |
|    b. Measurement, assessment, evaluation |
|    c. Encounters and shared spaces |
| 5. What do you value from this or that experience in particular? |
| 6. Related to this, what in your view are the main challenges and obstacles in the strengthening of users organisations in Chile? |
| 7. Do you have an image of what kinds of users and organisations could participate, and to what extent? |
| 8. According to the last version of the WHO AIMS, In Chile, users organisations are weak and unarticulated. Do you agree with this? |
| 9. What do you think are the main reasons for this? |

## Questions for service users and caregivers participating in organisations

| |
|---|
| 1. What are the origins and the main goals of this organisation? |
| 2. What are the main current activities and processes developed by this organisation? |
| 3. In relation to the Chilean mental health system and mental health services, what are the things that this organisation is trying to achieve? |
| 4. And how are you doing this? |
| 5. How do you evaluate the relationship between this organisation and the mental health system or services? Why? |
| 6. According to the last general evaluation from the WHO AIMS, in Chile, user users are still disorganised and their presence in policy is weak. Do you agree with this evaluation? Why? |

| | |
|---|---|
| 7. | The WHO has recently asked for the involvement of users in mental health policy across the world, what is your opinion about this and the role of users? |
| 8. | What kind of user organisations should be involved in the main decisions concerning the mental health policy of the country? |
| 9. | And what precisely can users contribute, as different from other groups such as caregivers? |

*D. Coding framework for interview transcriptions.*

| Category | Codes |
|---|---|
| User organising practices | Initial actions; Original vision; Networking; Goals; Heterogeneity; Identity; Representation; Role(s); Autonomy; Critical ideas; Solidarity; Tensions; |
| Mental health system and participation | Civil Society; User-Organisations; Funding; Global policy guides; Evidence; Professionalism; Policy transformations; Family organisations; |
| Barriers to participation | Cultural; Legal; Economic; Family as a barrier; Health condition; Treatment |
| Beyond mental health system | NGOs; Legal system; Political system; The State |

## 3. Paper 2

*A. List of Interviews*

| Date | Pseudonym | Profession | Position |
|---|---|---|---|
| 20/08/2015 | Alonso Jimenez | Psychiatrist | Central Level |
| 20/08/2015 | Lidia Hernandez | Social Worker | Central Level |
| 08/10/2015 | Fabio Diaz | Psychiatrist | Central Level |
| 02/10/2015 | Claudio Farías | Psychologist | Central Level |
| 27/08/2015 | Laura Vega | Psychiatrist | Local Level |
| 24/08/2015 | Julio Soto | Psychologist | Local Level |
| 25/08/2015 | Daniela Silva | Social Worker | Local Level |
| 04/09/2015 | Oscar Ulloa | Psychologist | Local Level |
| 10/09/2015 | Miguel Lara | Occ. Therapist | Local Level |
| 28/09/2015 | Karen Solis | Social Worker | Local Level |
| 10/09/2015 | Adán Bravo | Psychologist | Local Level |
| 11/09/2015 | Manuel Montes | Psychiatrist | Local Level |
| 01/09/2015 | Jorge Perez | Psychologist | Local Level |
| 23/09/2015 | Sonia Jerez | Psychologist | Local Level |
| 10/09/2015 | Mirella Cid | Psychologist | Local Level |

| 08/10/2015 | Rosa Tapia | Service user | Local Level |
|---|---|---|---|
| 08/10/2015 | Bruno Cepeda | Service user | Local Level |
| 14/09/2015 | Cesar Ayala | Service user | Local Level |
| 05/10/2015 | Renata Veliz | Service user | Local Level |
| 05/10/2015 | Luz Jara | Service user | Local Level |
| 11/09/2015 | Sol Puente | Service user | Local Level |

## B. Settings for Participant Observation

| Date | Place | Type | Description | Hrs |
|---|---|---|---|---|
| 24/08/2015 | SSMSO[1] | Mental Health Team Technical Meeting | Regular meeting, administrative mental health team and user representatives. | 2 |
| 26/08/2015 | SSMSO | Mental Health Team Technical Meeting | Regular meeting, administrative mental health team and user representatives. | 2 |
| 02/09/2015 | Day Hospital, CASR[2] | Day Hospital Team Meeting | Meeting with professional team and users of the Day Hospital. | 2 |
| 23/09/2015 | SSMSO | Mental Health Team Meeting | Extraordinary meeting to discuss a draft version of new National Mental Health Plan, with user representatives | 4 |
| 28/09/2015 | SSMSO | Community Mental Health Network Meeting | Regular meeting of the CMHN | 3 |
| 01/10/2015 | CESFAM Alejandro del Rio[3] | Puente Alto Community Mental Health Network Meeting | Regular meeting of the Puente Alto (commune) CMHN | 3 |
| 21/10/2015 | SSMSO | Community Mental Health Monitors Meeting | Extraordinary meeting with recently trained CMH monitors | 2 |

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[1] South East Health Centre, Puente Alto, Santiago.
[2] Sotero del Rio Health Complex, Puente Alto, Santiago.
[3] Puente Alto, Santiago.

*C. Topic guides for interviews*

<u>Topics and questions for professionals at central and local levels</u>

| |
|---|
| 1. Current position and role in this health service/facility |
| 2. Current processes and main challenges in your work |
| 4. Projects and concrete actions on service user involvement (Plans, meetings, encounters) |
| 5. Assessing/evaluating these experiences |
| 6. WHO AIMS: Do you share this image? |
| 7. Personal evaluation about the current state of user's organisations |
| 8. Main challenges for services users to participate |
| 9. How do you imagine an influential user group |
| 10. The specific contribution of service users |
| 11. What can your organisation do to promote or hinder that contribution? |

<u>Topics and questions for users at the local level</u>

| |
|---|
| 1. Origins and aims of your organisation |
| 2. Main activities of your organisation |
| 3. What changes are you trying to bring to mental health services? |
| 4. Visions about the interaction between mental health services and users |
| 5. Personal evaluation and opinion about the current status of service user organisations |
| 6. WHO AIMS: Do you share this image? |
| 7. What's the specific contribution of users and their organisations to mental health services/policies? |

*a. Coding framework*

| Category | Codes |
|---|---|
| Institution | Community model; Psychiatry; Relationship between MH/GH; Participation mechanism; Primary Health Care; Ideal organisation; |
| Community | Education; Ideal relationship; Concrete relationship; Invitations; As resources; As risk |
| Limitations to participation | Resources; Human resources; Time; Bureaucracy |

| | |
|---|---|
| Users and Representatives | Organisations; Influence; Leadership; Self-help; Origins; Family dynamics; Burnout; Roles; Religiosity; Professionalisation; Ego; Altruism; Passivity; Monitors |
| Professionals | Roles; Training; Paternalism; Personal qualities |
| Social transformation | Transformation; Ideals; Horizons |

## 4. Paper 3

*A. List of sites and dates of participant observation*

| Date | Place | Type | Group | Description | Hrs |
|---|---|---|---|---|---|
| 27/07/2015 | Santiago | 2nd International Conference on Stigma | ALM | International conference described in the introduction to paper 3 | 4 |
| 27/07/2015 | Santiago | Agrupación Libre Mente (ALM) weekly meeting | ALM | ALM regular Monday evening meeting | 2 |
| 28/07/2015 | Santiago | Centre for Critical Action in Mental Health (CACS) weekly meeting | CACS, ALM | CACS regular meeting | 3 |
| 30/07/2015 | Santiago | ALM extraordinary meeting | ALM | Meeting exclusively dedicated to the workshop project | 3 |
| 03/08/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 2.5 |
| 05/08/2015 | Valparaiso | Radio Diferencia (RD) Weekly Radio Show Meeting | RD | Weekly reunion to produce and record the radio show. | 3 |
| 08/08/2015 | Santiago | Reunión creación federación discapacidad | RD | Meeting of disabled peoples organisations (DPOs) whose object was to develop a national alliance of DPOs. A representative from RD was invited | 3 |

| Date | Location | Event | Organisations | Description | |
|---|---|---|---|---|---|
| 10/08/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 3 |
| 14/08/2015 | Valparaiso | ANUSSAM Assembly. | ANUSSAM, ALM | Formal meeting in which ANUSSAM selected a new directory. Members of ALM were invited. | 3 |
| 17/08/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 3 |
| 19/08/2015 | Santiago | Human Rights Manual Presentation | ALM | Leader of ALM presenting the Manual to a group of students and academics in public health. | 2 |
| 04/09/2015 | Valparaiso | ANUSSAM - ALM reunion | ANUSSAM, ALM | Closed meeting organised by ALM and ANUSSAM to know each other and make plans together. | 3 |
| 07/09/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 3 |
| 21/09/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 3 |
| 25/09/2015 | Valparaiso | "From patient to expert by experience Event" | ALM, ANUSSAM | Public event organised by ANUSSAM and ALM to share their vision to psychology students | 4 |
| 05/10/2015 | Santiago | ALM weekly meeting | ALM | ALM regular Monday evening meeting | 3 |

| Date | Location | Event | Organisation | Description | Days |
|---|---|---|---|---|---|
| 09/10/2015 | Valparaiso | ANUSSAM meeting with students | ANUSSAM | ANUSSAM special meeting with psychology and sociology students | 2 |
| 16/10/2015 | Santiago | ALM Extraordinary meeting | ALM | Meeting organised to share my experience and part of my project with ALM | 3 |
| | | | | | **52.5** |

# ANNEX 2: ETHICS REVIEW APPROVAL

**LSE** THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE ■

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Research Division

Cristian Montenegro
Department of Methodology
c.r.montenegro@lse.ac.uk

6th August 2015

Dear Cristian

**Re: User Organizations and the Chilean Mental Health System. Observing the construction of an emergent boundary**

Ref # 000396

I am writing with reference to the above research proposal, in respect of which I have had sight of the research ethics review conducted by you and your supervisor, Dr Flora Cornish. I can confirm that your review has been conducted in full accordance with the School's Research Ethics Policy and Procedure. Dr Cornish's approval of your project is sufficient having regard to the authority afforded to suitably qualified and experienced research supervisors where there is evidence that proper attention has been given to such ethical issues as may be raised by a project, where safeguards have been considered, and the risks entailed are minimal.

I would like to take this opportunity to wish you well with your research project.

Yours sincerely,

Lyn Grove
Research Governance Manager