

**NEW PROGRAMS IN THE OLD ASYLUM: THE DEINSTITUTIONALIZATION OF  
LONG-TERM PSYCHIATRIC HOSPITAL PATIENTS IN ARGENTINA**

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*For Celestina and Roberto*

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## Abstract

Large psychiatric hospitals with inpatients interned for decades are still the norm in Argentina, where deinstitutionalization and community-based mental health care is almost inexistent. This thesis focuses on some changes taking place in a centenary psychiatric hospital in Buenos Aires province: the *externación* of long-term psychiatric patients through new programs planned and run from inside the institution by health professionals compromised in making a change in the old asylum. Can long-term inpatients with serious mental illness such as schizophrenia leave the asylum and integrate in the society having a recovered life? Do the new *externación* programs make this possible? What is the place of the psychiatric hospital in the process of *externación*? are some of the questions raised in this research. Through an ethnographic methodology it describes the ex-patients' experiences of life inside the institution, going through the *externación* process, and living outside in the community. These experiences provide insider perspectives to analyze the new programs and also the place of the psychiatric hospital in ex-patients' lives in the community.

The literature on deinstitutionalization in the United States usually describes the lives of ex-patients in the community as lonely, isolated, empty, and lacked of socially valued roles and productive activities. The findings of this research, instead, describe ex-patients lives as involved in an informal economy for coping with a context of poverty and scarcity of social security programs and official policies for deinstitutionalization. Ex-patients construct survival strategies and social networks and participate in the “outside world” of the community integrating aspects of the “psychiatric world” of the hospital, which they have constructed as a multiple resource, and making meaningless the supposed need of separating these worlds.

## Introduction

This thesis narrates the histories of women and men who spent most of their lives interned in Egidio Clovera Neuropsychiatric Hospital<sup>1</sup> in Buenos Aires province, Argentina, and who have recently moved out of the Hospital to live in ordinary neighborhoods. It also describes the *externación* programs that made their movement possible. In Argentina, the term *externación* describes a process of moving out from an *internación* (internment) in institutions; it does not per se imply deinstitutionalization and it does not necessarily imply medical discharge either<sup>2</sup>. The *externación* programs are projected, implemented, and run by few professionals from Clovera Hospital and are oriented to *externar* patients working from within the institution and in a context of lack of legislation, policy, and budgeting for deinstitutionalization in Buenos Aires Province.

The object of my research was to analyze the achievements, difficulties, and problems of the *externación* programs in light of the ex-patients' experiences of deinstitutionalization, the particular socio-politic and economic context of Argentina, and the deinstitutionalization process in the United States and other countries'. I want to show whether people diagnosed with serious mental illness who have been long-term psychiatric inpatients can leave the Hospital, deinstitutionalize from the negative aspects of mental institutions, and integrate in the community having made a successful recovery. Presently, neuropsychiatric hospitals are being debated in the medical and political sphere in Buenos Aires. Drawing on insider perspectives, this study throws light on the ambivalent nature of these institutions.

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<sup>1</sup> The name of the hospital, as well as the real names of all the persons who appear in this thesis has been changed in order to preserve privacy and confidentiality.

<sup>2</sup> I will talk about the programs and the process of leaving the Hospital as *externación* programs or process, and about the ex patients as being *externados*. The ex-patients participating in my research are *externados* but not all of them have a definitive medical discharge from the Hospital, but a weekly renewed certificate of discharge. *Externación* means that they are not living in the Hospital any more, and that they are not "patients" any more in the sense of being an inmate or psychiatric hospital inpatient.

Also, it incites us to think about what kind of society we have and what changes would be needed for a better integration of ex-patients and people with severe emotional distress.

I hope that this thesis will contribute to the future development of the *externación* programs studied here, as well as to other projects and programs oriented to a transformation of the mental health system that takes into account insider points of view and previous experiences of difficulties and accomplishments.

### **The Ex-Patients**

The men and women whose histories I will narrate through the following chapters, and that I call ‘ex-patients’<sup>3</sup>, were long-term psychiatric inpatients with a mean length of stay in Clovera Hospital of 21 years and a mean age of 52 (n=10). They have been diagnosed with serious mental illness, mainly schizophrenia, but also mixed diagnoses which may have varied over time, such as paranoid psychosis, epilepsy, mental retardation, alcoholism, neurosis, and affective disorder. But despite their diagnoses, their long hospitalization and their advanced age, all seen as negatively influencing the desire and capability to leave the Hospital, they are all constructing their lives outside the institution.

I met Ayilin, Rodrigo, Celeste, María, Mariano, Ester, and Pino<sup>4</sup> at Egidio Clovera Hospital during 2002 and 2003, while I was doing fieldwork for a master’s thesis in anthropology with the aim of describing and understanding the meanings of the institution for

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<sup>3</sup> When I use the term “ex-patients” or “former patients” it implies that they are not “patients” any more in the sense of inmates. They are still patients of the hospital but other kind of patients now (“ambulatory patients”, out patients). I do not use the terms “consumer”, “client”, or “user” common in other countries because they are not used by ex patients in Buenos Aires province (or to my knowledge in the rest of the country). The terms are not used by the general public either, and are rarely used by health professionals. When health professionals, especially social workers, choose to call patients or ex-patients with a different term, they use “clients” or “users,” not “consumers.” The association of this last term may be positive and even progressive in American culture, where it refers to positive values such as freedom, democracy, free-market, or free enterprise. But in Argentina, “*consumidor*” (“consumer”) is negatively associated to “*consumismo*” (the act of shopping indiscriminately or indiscriminately wasting resources). Particularly, I do not like the term because of its commercial connotations for medicine (providers selling their services to consumers who shop and choose them, a strange reality for poor people in Argentina who rely on public medicine. The same applies for the term “client” or “costumer.” I have no objections to the term “user,” (“*usuario*”) employed by Brazilians, but it is not commonly used, and is rather associated with the use of domestic services and for drug addicts.

<sup>4</sup> Most of them selected the pseudonym used here.

employees, neighbors and inpatients. Even most of them had told me about projects and desires of leaving the Hospital, I never considered it as a feasible possibility, as almost anybody did. In June 2004, ten months after I had finished my fieldwork, I went to the Hospital to visit them and I was positively shocked with surprise: María, with 55 years and almost four decades of internment, had left Clovera and was living with two other women, Mercedes and Sofía, in a *casa de convivencia*<sup>5</sup> rented by the Hospital. Pino and Mariano were also living in a *casa de convivencia*. In January 2004 I went again to the Hospital and I was told that Celeste and Rodrigo had also moved out of the institution and were living together in a small house that they rented by themselves. Celeste was 55 years-old with 34 years of institutionalization behind her; Rodrigo was 53 and was interned for 20 years. I visited them in their house and the happiness expressed in their voice and in their eyes, together with my impression of their amazing courage, motivated my desire to write about their experience.

In June 2005 I started my fieldwork, and this time all of them, Ayilin, Rodrigo, Celeste, María, Mariano, Ester, and Pino had left the Hospital, together with other patients. Deinstitutionalization of the long-term mentally ill does not sound new in the United States and other developed countries, but it is something out of the ordinary in Argentina and specifically in Buenos Aires province, where no mental health legislation regulates or mandates deinstitutionalization, and no community-based mental health care system exists.

As I will show in chapter one, at the Hospital all of them had a life of “mortification of the self” (Goffman 1962), affective and material scarcity, and lack of privacy and freedom, even though they resisted some of the negative consequences of institutionalism. Their lives prior to their hospitalization, as they described it to me, were also lives of poverty, family problems, maltreatment, political persecution, or abandonment.

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<sup>5</sup> *Casas de convivencia* are transitional houses that differentiate from half way houses in that they are inhabited exclusively by patients with no staff in charge and without delimitation of the length of stay.

Rodrigo is a friendly and affectionate man, tall and big, with short “salt and pepper” hair and mustache. In his youth, Rodrigo and his brothers were involved in a left-wing political movement in Buenos Aires, and during the seventies they suffered the State terrorism of the “Process of National Reorganization”, the last Dictatorship government in Argentina’s History. His two brothers were *desaparecidos* and he hid in a small costal city. His mother died of sadness. He later returned to Buenos Aires City and had several occupations, such as chef’s assistant, bus driver, and track conductor. He got married and had a daughter and a son, but then abandoned them when they were children. He was living with his sister when he had one of his *crisis de nervios*<sup>6</sup>, and he started ambulatory psychiatric treatment at a public psychiatric hospital. After having an accident, he needed long hospitalization because of several surgeries in his ankles and knees, and after six month at a general hospital he was transferred to Egidio Clovera, where he remained twenty years. He met her present common-law partner Celeste at Clovera Hospital, around nine years ago.

Celeste is a short woman with short and straight dark-red colored hair with bangs. Her black eyes are bright and kind, and she is very timid. She likes to write short love poems and is highly affectionate. She was born in a southern province, from which she moved to Buenos Aires at the age of fourteen. Two of her sisters migrated first, when her younger sister needed hospitalization at a children’s hospital in Buenos Aires and her older sister got a job as a maid while she was taking care of the child. When Celeste migrated she lived for a while with her sister and then she also got a job with a family, as a maid and babysitter. When she had a *crisis de nervios* she was interned at Clovera Hospital, and the family told her that they would wait for her. But when she left the Hospital after one month the family had hired another woman, and Celeste could not find a job. She became demoralized and returned to the Hospital for thirty-four years.

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<sup>6</sup> *Crisis de nervios* (nervous crisis), is a folk category used in Latino America to express emotional distress (what psychiatry call mental illness). See explanation in page 18.

María has a thin and large face with bangs and a very long dark brown hair that she always keeps in a pony tail. She is a little overweight and timid, and she does not speak very much. When she got sick and had a convulsion, her mother interned her in another psychiatric hospital when she was fifteen years old, and then she was transferred to Egidio Clovera, where she spent 39 years. Now, María lives with Mercedes and Sofía, other long-term inpatients, in a house rented by the institution, a *casa de convivencia*, in an urban neighborhood.

Mercedes is a 72 year-old lady who spent 25 years interned at Egidio Clovera Hospital. She is small and skinny, with long grey hair, and is called “*la abuela*” (the granny). She was married and had children before being interned at the Hospital, but she does not see her sons.

Ayilin is a 41 years-old woman, with a round face with big front teeth and bright and straight black hair which reaches her shoulders. She is overweight and she always complains about that, since she used to be thin when I first met her. She is distrustful, especially with men, and reserved. But she is kind, affective and talkative with the people she likes. Ayilin rented a room for herself in a *pensión*<sup>7</sup> at the center of the city after having spent 23 years of her life at the Hospital. She was born in another province but her family moved to Buenos Aires, where she was interned in an institute. After finishing seventh grade, Ayilin could not go to high school and lived with nuns working as a maid. Later, she lived again with her family, and she suffered maltreatment, especially from one of her brothers who would get drunk and beat her repeatedly. Her illness appeared there. She started feeling “*desamparada*” (helplessness, abandoned) and stopped seeing people. She spent four months with her family, “four months that appear to me years. I didn’t like living there at all. I was 17 years old and I was weak, skinny, small. I lost contact with people, I was not “*ánimicamente*” (in good spirit)

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<sup>7</sup> A *pensión* is an old large house with several cheap rooms for rent.

well.” Ayilin then decided to depart from the house, and she ended in an institution until a social worker sent her to Clovera Hospital. “I wanted to get out from that institute. Wherever they wanted to send me was fine to me.”

When I started the fieldwork for this research Pino, Pedro, Mariano, and Daniel were living in a *casa de convivencia*. Pino is 50 years old and spent 20 interned at the Hospital. He is a thin and tall man, with short dark brown hair. He is extremely social and friendly, and talks very fast. He is always smiling and ready to help others. Pino was born in Spain and immigrated to Argentina with his mother when he was seven years old. He did not have a father or brothers, and when he was 18 his mother died.

Pedro is also 50 years old. He is lightly overweight, of medium stature, and has short black hair. He is calm and speaks slowly and kindly, and he is very cordial. He spent three years at Clovera Hospital before being selected to leave the Hospital and joining the house with the other men. When he was a child, he went to a special school because he failed in the regular one, which he says was too fast for him. He got married and had a son, and lived with his parents until his mother died. Then, he went to live with his wife and brothers-in-law. When his wife got sick and died, he continued living in the house with his brothers-in-law, but they threw him out when he invited a girlfriend to live there. “She was a bad woman,” he says. He moved to another city and lived as a homeless in the surroundings of a general public hospital, where he washed cars in the parking lot and slept on the benches. He arranged to rent a *pensión* room with other men, but one of them was a drunker and life was impossible with him. He started seeing his son during a short time, but he did not receive him well. Another of his partners at the *pensión* made arrangements so that he could be interned at Clovera Hospital.

Daniel is 47 years-old man, tall and thin, with a mustache and short curly brown hair. He is serious, but talkative. Daniel was interned for four years at Clovera. Before that, he

lived in different cities, got married and had two sons, who are now adults. But his marriage was all bad and he was only treated well by his mother-in-law, who died.

Mariano is a 49 years old man, with a round face and relatively long and straight dark hair, with some grays. He is serious and rarely smiles. He spent 21 years in the Hospital before moving to the *casa de convivencia*, where he lived more than two years. He left the house just when I finished my fieldwork, and went to live with his girlfriend Ester in an independently rented house. Ester is 42 years old; she is a slim and tall woman with medium large and curly light-brown hair. She is a joyful person with vivid eyes and very talkative. She spent twenty years interned at Clovera, before moving out with Mariano.

\* \* \*

The life histories of these men and women, from inside to outside the institution, are narrated through the chapters of this thesis. In chapter one I describe the past and present of the State Mental Hospitals and Egidio Clovera Hospital in particular, showing how was life for the ex-patients inside the institution. Chapter two is about the new *externación* programs and shows the possibilities patients have for moving out of the Hospital, while chapter three describes one program in particular and the ex-patients' experiences going through that program and moving out from the Hospital. In chapter four I describe the ex-patients' life outside the Hospital and in chapter five I analyze their social interaction and their integration into the community. Chapter six gives an overview of the problems of "deinstitutionalization" in the United States and looks at the Argentinean experience in a contrast perspective. Finally, chapter seven provides some conclusions about the significance of the new programs, the ex-patients' experiences, and the place of the psychiatric Hospital in the *externación* process.

### **Field Work and Methodological Issues**

I did field work at Clovera Hospital and the new residences of ex-patients from the beginning of June 2005 to the middle of August, and again in January of 2006. I first entered the field, however, in 2002, when I did a year and a half of fieldwork at the Clovera Hospital

and Town for my first thesis “*Los sentidos de Clovera. Una mirada antropológica sobre la construcción social de un espacio hospitalario*”<sup>8</sup> (“The meanings of Clovera. An anthropological view on the social construction of a hospital space”). A close relative of mine, who is a physician at the Hospital, introduced me to the staff working at a new cultural centre of the institution, and I met there patients and employees who participated in my research. I was interested in understanding what Clovera Hospital was for those “chronic patients” and low-employees/neighbors that daily interact in the institution and construct the hospital space beyond its medical dimension, in its social and economical aspects. My interest was far from the medical world, and I remained far from my father’s area of influence as well as from the psychiatrists of regular chronic wards. I did, however, conduct a few interviews with health professionals in charge of new programs for the rehabilitation and *externación* that called my attention, and which I have now studied in this project. I used the field notes of those previous interviews, as well as some tape-recordings and field notes of conversations with patients, as complementary data for this thesis.

In order to research my new topic, I did fieldwork at the ex-patients’ new residences outside the Hospital, as well as in the Psychosocial Rehabilitation Center (PSRC) where all the ex-patients whose stories I narrate here lived before their *externación*; I also did some interviews in the Day Hospital and the Pre-Discharge House (P-DH). I observed and talked with health professionals there, and with the ex-patients who go there frequently. I also had some conversational (informal) interviews with a professional from a dependence of the Justice that exerts tutelage on psychiatric patients; with a psychiatrist from a chronic ward; and with store-owners (mostly neighbors) from the middle class urban zone where both the Pre-Discharge House and the *pensión* where several ex-patients (Ayilin among them) live are located. Because I looked at the new *externación* experience in Argentina having in mind the

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<sup>8</sup> Thesis for a Master degree in Social Anthropology at San Martin University, Argentina (Dillon 2005).

process of deinstitutionalization and the mental health trends in the United States, I also did participant observations during three days of peer-support training, conversations with “consumers”, and an interview with a social worker specialized in mental health in the United States.

Since the Fall of 2004, I have been living and studying in the United States, where the mental health system has completely changed since the 1960’s with its pioneer process of deinstitutionalization. When I went to Argentina to do fieldwork for this thesis, I had in mind the history of deinstitutionalization in the United States. I looked at the first steps towards a mental health system transformation in Argentina from my knowledge of the problems and deficiencies as well as the exemplary programs and achievements of this process in the US and elsewhere (Torrey 1997, Swartz 2002, Shadish et al 1989, McCourt Perring 1993, Krieg 2001, Johnson 1998, Estroff 1981, among others). However, as I realized in the field, Egidio Clovera Hospital’s and Argentina’s socio-political and economical reality have particular characteristics that differentiate it from those of the United States. Therefore, the mental health programs and the experiences of ex-patients experiences can be compared only in some of their aspects to those of other countries but they have to be considered and understood in light of the specifics of the Argentinean context, with all of its own particularities.

I explained to ex-patients and health professionals my research objectives and my situation as a graduate student in anthropology at Louisiana State University in the United States, and they decided to participate<sup>9</sup>. I did not ask ex-patients to sign any written informed consent because one of my aims as ethnographer was to separate myself from the Hospital health workers, and they routinely use informed consents. The recently released ex-patients had previously gone through the experience of signing informed consents, and I did not want

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<sup>9</sup> There was one exception, and it was one of the ex-patients. I explained my project to Sofía and at the beginning she was positive about participating, but when I started writing something that María had told me, she became undecided and unconfident, she misunderstood my explanations of why I wanted to use a pseudonym instead of their real names, and decided not to participate. After that day I saw her a couple of times and we talked; she was happy to see me and invited me to her house, but I told her that I will not write her life story.

them to identify me as part of the mental health care system; I wanted to obtain their confidence and their understanding that anything they told me would not harm or prejudice them.

All health workers showed, in different degrees, an interest in my research. They always welcomed me, and although they were always busy and it was difficult to formally arrange a time to talk, they gave me part of their time. With the ex-patients, I always felt welcome; they were kind and enthusiastic in telling me their histories and sharing their time and activities with me. Ayilin, Celeste and Rodrigo gave me the role of a friend, a friend who was also doing research about them. For the rest, I think, it was clear that I was a student. I did not ask health workers about ex-patients address or any other fact, and I never saw their clinical records (*historias clínicas*). I was already in contact with Celeste and Rodrigo, whose address was given to me by a patient friend of theirs. I met Ayilin at the Hospital grounds and she gave me her address in the *pensión*, inviting me to visit her, and the same happened with Pino and María. They introduced me to their house mates later. The selection of ex-patients for my research was not based in their diagnosis, nor was it based on any criteria, such as of length of stay in Hospital, length of discharge, etc. I just selected those persons who I knew during my previous research and who had been recently *externados* through the PSRC, and they introduced me to Mercedes, Sofía, Pedro and Daniel, who I did not know before. They were long-term patients, an important fact for my research, but this is nothing extraordinary at Clovera. What was extraordinary was their *externación*.

The ex-patients, when they were at the Hospital, were not passive institutionalized “chronic patients,” even though they were not exemptions either. I met them because they participated in activities such as the exchange club or a carnival, classes at the cultural center or the theater, or because they were always present at the Hospital grounds or at the door and bus stop. They were part of the Hospital population that resists institutionalism (passivity, flatness, isolation, and other attitudes and changes produced by the hospital routine). The

*externación* of other kind of “patients,” those who need permanent assistance and a stronger rehabilitation, does not exist in Buenos Aires Province. The new *externación* programs thus far focus on people who may be ready to live alone and to have the medical discharge to leave the Hospital.

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I used in my research an ethnographic methodology, which is primarily qualitative, based on the techniques of participant observation and conversational interviews. I did not use formal structured interviews, especially with ex-patients, because I agree with McCourt Perring that “formal interviews are often an inappropriate and inaccurate way of eliciting their experiences. They hold too many associations with the diagnostic or medical interview, in which the person feels examined and tested” (McCourt Perring 1993:3). I had conversations that I wrote down later in my field notebook, or sometimes I took notes in their presence when dates and successions of success would be difficult to remember later (especially with health professionals). I also did a few more formal interviews with some of the professionals. Regarding participant observation, it was focused on the lives of the ex-patients. I was present at a relatively large range of their activities, and I observed their interactions at the Hospital (especially to the PSRC). I visited them in their homes, participating in activities such as cooking, drinking mate, eating lunch, cleaning up, or receiving visits, and I also spend time with them in the streets, jobs, stores, and buses. I spent more time with those ex-patients, whom I knew best from my previous research and with whom I had started a friendship: Celeste, Rodrigo, and Ayilin.

I rely exclusively on ex-patients’ own perspectives for the narration of their life experiences prior to, during and after their hospitalization. I recognize that these accounts may be incomplete and not exactly accurate, but they represent how they view themselves or how they wanted other people to know them. Therefore, I did not pretend to check their accounts

with those of health workers, putting in doubt what ex-patients say and giving alternative (medical) explanations for their behaviors and life events.

Since time to talk with health professionals was always scarce, my conversations with them were more focused on specific research questions. I talked with four psychologists, four psychiatrists, two social workers and two nurses about the objectives, difficulties, and origin and organization of the *externación* programs. My interviews with health professionals were not centered on the life experiences of ex-patients after or before their *externación*, but on the programs themselves. I also paid close attention to what they expected of ex-patients after their *externación*, how they expected that their lives should be after leaving the hospital.

My first concern with ex-patients was to differentiate myself from health workers, and to make clear that my work with them was for the University where I was student and that it was completely separated from the Hospital interests and from my relative working at the Hospital, in particular. I am different, in the clothes and accessories I regularly wear, from most health professionals. I normally do not use high heels or skirts and make-up. When I visited ex-patients I paid attention to wear ordinary clothes such as the clothes they wear (tennis or work shoes, jeans, T-shirts, sport sweaters, etc.). As Guber (2004) says, in the personal presentation of the researcher clothing and personal arrangement have a central part. But as also Guber (2004) recognizes, the mere use of the same cloth as the informants does not guarantee the bridging of the distance between researcher and informants. I think that sharing *mate* with ex-patients, greeting them with a kiss (two things that staff almost never do at the Hospital), and traveling with them by bus and sharing my own problems (as student in a foreign country, paying rent, looking for jobs) made them feel comfortable with my presence, and I also felt comfortable with them. In her study with psychiatric clients in Madison, Wisconsin, Sue Estroff (1981) narrates the distance and suspicion created by her first refusal to share marihuana and alcohol with them and how difficult it was for her to show symmetry with them without sharing illegal behaviors. I refuse smoking (something that almost all ex-

patients do) but drinking *mate* with them was both easy for me and appreciated for them<sup>10</sup>. I did not have, however, the same degree of trust and rapport with all the ex-patients, because for different circumstances I spent more time with some of them than with others<sup>11</sup>.

### **Conceptual Considerations**

The concept of “deinstitutionalization” appears largely in this thesis, because one of my purposes is to assess whether ex-patients were experiencing deinstitutionalization or not. As it is usually understood, deinstitutionalization implies the closure of mental hospitals and the creation of a new system of mental health care in the community (Bachrach 1989). It may seem wrong to talk of deinstitutionalization when there is no hospital closure and community-based care system available in Buenos Aires province. But as McCourt Perring (1993) argue, deinstitutionalization should be seen as

“a concern with a removal or alteration of those forms of control which negate the person’s previous identity, replacing it with that of patienthood, a permanent sickness role . . . deinstitutionalization requires the restoration of self respect and the ability to make constructive choices, in order to achieve the autonomy which is culturally considered essential to a valued, rather than deviant, social role” (McCourt Perring 1993:209-210).

Deinstitutionalization and community-based mental health care (the provision of services such as half way houses, group houses, day centers, sheltered workshops, advocacy, crisis attention, and other, in the community) usually suffer of unrealistic expectations and idealist romanticism. People can carry the institution within even after the mental hospital does not exist any more, and they may be view by the staff of the community services in the same way as they were previously viewed by the staff of the mental institutional. In my research, I try to

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<sup>10</sup> The act of drinking mate (Argentinean green infusion made from the dry leaves of *yerba mate*) is a social act because is done among friends, partners, or family, and it is intimate because implies the sharing of a straw from which you have to suck the liquid. Health workers do not share mate with patients at the Hospital.

<sup>11</sup> Ayilin, Celeste and Rodrigo were closer to me from my previous research than other ex-patients, and it was easy to find them at home since I knew Ayilin’s schedules and I could phone Celeste and Rodrigo to their neighbor’s house to arrange my visits. I was also close to Pino and María, but it was more complicated to find them at home. I went four times to María’s house before I found her there. Pino and his house mates arrived at their *casa de convivencia* at nightfall every day from their activities, and since it was very far from my house I only went once. Instead of visiting them, I saw them at the Hospital when they went there for visiting boyfriends/girlfriends, working, taking their medication and food supplies, etc.

understand whether the professionals in charge of the new programs allow or encourage ex-patients to deinstitutionalize themselves in this way, and whether ex-patients remain stuck in their patient role or “deinstitutionalize” themselves acquiring new attitudes and participating in the life of the larger community.

I use the concepts of “normalization” to understand both what are the expectations of the health professionals and to what degree ex-patients achieve a “normal” life.

“Normalization is a confused concept which historically has two meanings,” writes Kelly Johnson (1998: 157). One of its meanings implies ex-patients’ adaptation to socially accepted behaviors, values, and rules, in order to “pass” or “fit” in society. This approach to normalization places pressure on ex-patients to make changes to seem “normal.” The other meaning of “normalization” is more focused on the environment made available to ex-patients where they can have a life as close as possible to a regular life; it places pressure on society (and mental health services and facilities) to make the effort to integrate the ex-patients, who have the right to have a life in the community. I analyze the ex-patients’ life outside the Hospital and the health professionals’ approaches to their *externación* taking into account both meanings.

Regarding the concept of “recovery”, I assume in this thesis that people can recover from mental illness and have a normal life. The usual belief of the mental health system in developed countries is that people do not recover from illness such as schizophrenia. Only recently, during the past ten years, the concept of recovery has gained validity in the United States. As it is understood by consumers in this country, a person is recovered from mental illness when she/he can make decisions, has achieved a major social role/identity; takes medication as a tool among many others freely chosen; is capable of expressing and understanding emotions and coping with severe emotional distress; functions pretty well and has some meaningful interpersonal relationships, and when most untrained people would not consider them sick. The concept of recovery is different from that of remission or

rehabilitation. Remission means the absence of symptoms while the person remains mentally ill. Recovery, instead, means that people should recover a full life, not simply achieve symptom reduction; rehabilitation is a useful concept but it is only a portion of recovering a life, since it requires a person to learn how to function in society but still remaining mentally ill.<sup>12</sup> The subjective meaning of deinstitutionalization defined previously implies recovery. I analyze ex-patients' lives after *externación* taking into account these characteristics, in order to assess their deinstitutionalization. As I see it, it is a process that requires the work and effort of the ex-patients themselves, but I also think that the characteristics of the neighborhoods where they are living, the expectations of health professionals, and other factors shaping the environment where they live are fundamental.

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Cecil Helman (2000) identifies three main approaches to mental illness. The biological approach, typical of traditional psychiatry and rejected by most medical anthropologists; the social labeling approach, opposed to the previous approach and preferred by some sociologists and some psychiatrists of the antipsychiatry movement; and combined approach to which most medical anthropologists subscribe. People sustaining the biological approach believe in the biological basis of serious mental illnesses such as major depression or schizophrenia, explained as a genetic defect caused by an imbalance in the chemical levels of neurotransmitters. As many authors enunciate, especially in the United States, the biological bases of mental illness is a theory officially accepted as a fact and sustained by the pharmacological industry, but it is controversial because of the lack of proof. "The language of biological psychiatry is filled with 'implications,' 'maybes,' and 'possibilities' but short on documentation. . . . Psychiatrists have no biological or objective test to diagnosis mental illness" (Leo 2004: 47-48);

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<sup>12</sup> National Empowerment Center, "What are the Characteristics of a Person who has Recovered from Mental Illness?" By Daniel Fisher: <http://www.power2u.org/articles/recovery/characteristics.html>, consulted May 15, 2006.

The government states that ‘mental illnesses’ are brain diseases. Why then is the government’s multibillion dollar institution called National Institute of Mental Health? Why isn’t it called the National Institute of Brain disease? Why isn’t it merged into the National Institute of Neurological Disorders and Stroke? Why do we need two separated institutes devoted to study brain diseases? (Szasz 2004: 427).

The health professionals working in the *externación* programs are opposed to the biological theory of mental illness, at least in its more radical ideas. Unfortunately, they say, most psychiatrists at Clovera Hospital adhere to it, and do not consider patients’ social context but only their symptoms.

The social labeling approach states that mental illness is a myth (Szasz 2004) created by society, because society decides which behavior are deviant or abnormal, and what type of deviance has to be called ‘mental illness’ (Helman 2000). This approach to mental illness negates its existence before the individual is labeled with it. Once the diagnostic label is applied, it is difficult to discard. Regardless of the important reflection on the diagnostic labels, this approach is usually criticized because of the negation of suffering beyond diagnostic labels. Antipsychiatry sometimes “degenerated into a glorification of insanity and into an extreme idealism which could de-emphasize the pain and misery experiences by many patients” (Brown 1985: 169).

I do not know if the ex-patients participating in this research have something wrong in their biology, but I know that there have been many terrible things in their life histories, and that they have suffered quite a lot. This suffering is real, as well as the severe emotional distress they developed. The last approach considered by Helman (2000) combines a strong critique of the labeling process and of the view of mental illness as brain diseases, but recognizes the psychic suffering as an illness and not just a disease. Following Arthur Kleinman’s distinction, *illness* implies psychosocial processes and being shaped by personal, social, and cultural reactions to the disease, and a *disease* is a malfunction of a biological or psychological process (Sullivan 1994).

Rosenhan (1998) does not call into question the existence of deviant or odd behaviors and the anguish associated with mental illness, but he questions the use of labels such as schizophrenia, bipolar disease, etc. He states that “normality and abnormality, sanity and insanity and the diagnoses that flow from them are less substantive than many believe them to be . . . . Psychiatric diagnoses are in the minds of the observers and are not valid summaries of characteristics displayed by the observed” (Rosenhan 1998:282). The boundaries between sanity and insanity and between the different types of mental illness are not clearly detected, and research has shown that there are difficulties in standardizing psychiatric diagnoses.<sup>13</sup> Helman (2000), in the same sense, says that “most psychiatric illness are based in doctor’s subjective evaluations of the patient’s appearance, speech and behavior, as well as performance in certain standardized psychometric tests. The aim is to fit the symptoms and signs into a known category of mental illness by their similarity to the ‘typical’ textbook description of the condition” (Helman 2000:177). As he demonstrated through his research<sup>14</sup>, having a label of schizophrenia may lead to a re-shaping of normal behaviors and personal history for showing ambivalence, affective instability, compulsive behavior, and other characteristics of schizophrenia.

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<sup>13</sup> Diagnostic practices differ in different Western countries. Through different experiments (such as showing videos to doctors in different countries and asking them to make diagnoses), it is known, for instance, that British and American psychiatrists perceive different symptoms in the patient’s behavior, and therefore they differ in their diagnostic practices (van der Geest and Finkler 2004); in the U.K. admissions for manic depressive psychosis are over ten times more frequent than in U.S. where, instead, schizophrenia is diagnosed more frequent. The British see less pathology in the symptomatology than U.S. physicians and therefore they diagnoses schizophrenia with less frequency (Helman 2000). Diagnoses practices differ even within the same country, according to the postgraduate psychiatric training; for instance, psychiatrist trained in Glasgow make more diagnoses of “affective illness” and less of schizophrenia than doctors from other Universities (Helman 2000).

<sup>14</sup> Rosehan’s original paper appeared in 1973 in *Science* 179: 250-58. The paper is based on an “experiment”: he and other researchers passed as pseudopatients in different psychiatric hospitals. After an admission interview in which they reported hearing voices of specific characteristics, they were interned with a diagnosis of schizophrenia (and one of them, with identical symptomatology, with manic-depressive psychosis). After their admission, they ceased simulating any symptoms of abnormality, but the pseudopatients were never detected by the staff. Instead, the tag of schizophrenia colored all the perceptions of them and their behavior. Otherwise normal behaviors were shaped by the diagnoses and seen as abnormal. The sources of deviance are located within the individual instead of within the complex of stimuli that surrounds him.

I decided to leave to psychiatrists and mental health professionals the medical or psychological analysis of ex-patients' lives in terms of their illness and what situations or disabilities occasioned by their illnesses would be difficult for them to overcome. I did not want to know their diagnoses when I was doing fieldwork, because I agree in that

a psychiatric label has a life and an influence of its own. Once the impression has been formed that the patient is schizophrenic, the expectation is that he will continue to be schizophrenic. . . Such labels, conferred by mental health professionals, are as influential on the patient as they are on his relatives and friends, and it should not surprise anyone that the diagnosis acts on all of them as a self-fulfilling prophesy. (Rosenhan 1998:287-288)

I did not want to look at the ex-patients' lives with the lenses of psychiatric labels. Terms such as "schizophrenia," "psychosis," or "manic depressive" describe, for the non trained public, a social conduct (potentially dangerous behavior!) rather than an illness. As "mental health consumer activists" in the United States explained to me, those who know about the labels have more stigma than those who don't know anything; there is more stigma in mental health professionals than in non-trained people in the neighborhoods. Therefore, I interacted with ex-patients being ignorant of their diagnoses<sup>15</sup>. They never talked about them, and rather refer to their illness in more acceptable and popular terms such as "*crisis de nervios*," a common Hispanic label of the folk culture used to provide explanatory frameworks to mental illness that are not stigmatizing and allow optimistic expectations about recovery (Sullivan 1994)<sup>16</sup>. Only Ayilin discussed with me one of her diagnoses (that of "moderate mental retardation").

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<sup>15</sup> During my previous fieldwork, as I narrate in the first thesis, I started interacting with patients, and one day I asked the diagnosis of a 24 years old girl. The description I obtained, that she was a psychotic and violent person from whom all nurses were afraid, did not correspond with my views of the girl I was talking to. That description impressed me so much that I became suspicious of her friendship and started expecting the madness to attack at any moment. I decided that that was the worse form of relating to the patients, and never again asked a diagnosis. I just considered patients people who has their private history of health.

<sup>16</sup> The *crisis or ataques de nervios* are expressions of emotional distress, folk alternatives to the different diagnoses of mental illness. As medical anthropologists state, "emotion" as a "lived experience within a cultural context rather than as an internal experience of an individual, as emotion is studied in American psychology, or as a symptom disorder, as emotion is often studied in American psychiatry"(Guarnaccia 1996: 343). As Scheper-Hughes and Lock (1983) argue, bodily expressions of emotional distress are more than individual experiences, since emotions "provide an important missing link capable of bridging mind and body, individual, society, and

Now that I have lost the fear and stigma that I had towards Clovera Hospital and its patients before and during the first days of fieldwork in 2002, I started to compare some of them and all of the ex-patients that I know with other people from my own neighborhood who have never been interned in a psychiatric hospital and who are not labeled with a mental illness. They have something rare, difficult to define. Some of them talk too much, others too little, some seem simple and ingenuous, others seem to hide something, but all are part of the community. Who does not have a neighbor or a relative who is a little crazy, or knows a depressive and lonely person? In a heterogeneous society, one of integration and not of exclusion, there is a place for people who may be different in many ways. Besides my decision of not allowing diagnoses to influence my relationship with ex-patients, I also wanted to respect their privacy, feeling that it was disrespectful to talk behind their backs with somebody in a position of power about things that they did not want to tell me.

When I finished my fieldwork for this project and started to write this thesis, I read about the usual belief in the impossibility of recovery for people diagnosed with schizophrenia, as well as how difficult it is for those suffering other serious diagnoses. I started thinking about whether it was important or not to know and write what diagnoses ex-patients have, because it may make more valuable their achievements. Therefore, I send an e-mail to Julieta, one of the psychologists from the PSRC, asking her about the diagnoses covered by the ex-patient population of my research, in general terms. Most ex-patients

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body politic”(1987:28-29).Guarnaccia (1996), studying the experiences of *ataques de nervios* in Puerto Rico, argues that “*ataques de nervios* are an idiom of distress particular prominent among Latinos from the Caribbean, but recognized among many Hispanic groups” (Guarnaccia 1996:345). According to this author, this idiom expresses dislocations in the social world of the family (news of death of a close kin, conflicts with spouse and children, etc), it expresses a threat to the person’s social order, a sense of loss of control over the social world that translates in a loss of control over the body. The symptoms are screaming uncontrollably, breaking things, fainting, attacks of crying, trembling, becoming verbally or physically aggressive, etc.

Other factors beyond dislocations of the family life, however, can influence *crisis* or *ataque de nervios*, as Nancy Scheper-Hughes shows. In her book about violence and everyday life in the *Nordeste* of Brazil, she includes a chapter about *nervios* linking *crisis de nervios* to the structural situation of hunger suffered by the Brazilian *nordeste* inhabitants. For them *nervios* and *nerviosismo* proportionate an idiom to reflect their hunger and the perturbations caused by it (1997:169). The nervous-hungry body is a metaphor of the socio-political system and the weak position of the rural worker in the economical order (Scheper-Hughes 1997: 185). She describes how indigence, hunger, and helplessness is expressed in the form and the idiom of an illness, and denunciates how biomedicine often approaches the problem of “*nervios*” just as a mental problem and medicalize the underlying socio-economical problem with pills for sleeping, tranquilizers, vitamins, etc.

(seven out of ten) resulted in having been diagnosed with schizophrenia, the terrible word, in some of them together with other diagnoses. We will see through this thesis how they did in their lives since they left the Hospital. From what Julieta told me in her answer, I know that I was not wrong in avoiding seeing ex-patients from the perspective of their labels. She indirectly said that the team of professionals of the *externación* programs has disagreements about patients' diagnoses, and that they are always re-evaluating them. Patients may have been misdiagnosed years ago, or their diagnoses could change over the time. Also, she said that multiple diagnoses are common.

## **Chapter 1**

### **The State Mental Hospital**

#### **The First Asylums**

According to Michel Foucault (1999), the idea that madness was possible to cure in a medical space and that the modern “insane asylum” was the best institution for that, was first envisioned by Pinnel and Tucke in France and England at the end of the eighteenth century (Foucault 1999: 190). Previously, the medical thought and the practice of internment were isolated from one another, and the mad were confined in jails and poorhouses together with marginal people. When Pinnel liberated the insane from chains and dungeons in Bicêtre, France, and when Tucke opened a paternalistic house without bars in the country side of England, they had a completely new idea regarding the “insane”; they finally recognized madness and the need of treating it medically. Madness was seen as an illness not of the individual body but of the society, as an alienation of the moral order. Recovering morality would bring the recovery of reason, and it was the asylum that became the place designed for doing that cure through the ideal forms and values of society: work, honor, authority, and sacrifice (Foucault 1999:190-263).

During the nineteenth century Pinnel’s and Tucke’s ideas were applied in America. The insane were purified from the old conception of animal violence, depravation, savagery and anger (Foucault 1999: 211), placed in “modern asylums,” and treated with a “moral treatment.” Authorities, physicians, philanthropists and the educated public started to speak of the benevolent and humanitarian act of opening asylums for the insane as part of the “enlightenment” and “progress” of the “civilization.” In the United States, asylums opened since the 1830’s but especially after Dr. Kirkbride’s treatise on hospital design of 1854. According with Dr. Kirkbride (1854), the custody and enlightened treatment of the insane were a duty of the States, and a “matter of humanity.” He did a detailed description of how asylums should be built, and many of them were built throughout the country. In Argentina

the first asylums were built in the 1860's, but a "modern" treatment was only put into practice during the first decades of the twentieth century. Clovera Hospital, where the ex-patients whose deinstitutionalization experiences I describe in this thesis were interned, opened at the end of the nineteenth century, and is still in function, even though the ideas of psychiatry have changed.

During the nineteenth century, according to Isaac Ray (1863), the founder of the American Psychiatric Association, the isolation and segregation of the "insane" in asylums were considered the best for them and for the society. For Kirkbride (1854), the hospitals for the insane were necessary for the protection of their families and the community from the acts and influence of morally irresponsible and dangerous persons. Architectural arrangements that restrain without annoyance, systematic regularity in daily routine of life, genteel manners, judicious firmness, and vigilant, enlightened and conscious supervision were the basics of moral treatment for Ray (1863). The architecture of the asylums had to offer possibilities for supervision, classification, comfort and treatment (Kirkbride 1854). The founders of asylums wanted to control a disruptive population while at the same time trying to care for them in a humanitarian way.

### **The First Critiques of the Asylums**

Advances of the twentieth century changed things considerably. Asylums were progressively viewed as in-humane places where no cure or "rehabilitation" was done, but just custody and segregation. However, the asylums, now called "mental hospitals," remained as the principal if not unique system of mental health care until recently in developed countries. Asylums are still present in many countries, where they are anachronisms since the moral treatment and the original idea of restoring the reason, curing the "insane" and putting them once again in society, has been abandoned a long time ago. Long term internment and chronicity was not common in nineteenth century asylums, but has been the norm during the twentieth century when mental hospitals became overcrowded with a population that got older

and stayed longer. Asylums abandoned their medical function for the custodial one. During the 1940's and 1950's public opinion toward asylums in the United States were negatively influenced by journalists who did investigations and descriptions of the bad conditions in which patients were kept in asylums. This situation inspired the critical writings of Foucault (1989) analyzing the power relationships and disciplinary technologies in those hospitals, the work of Goffman (1962) denouncing the mortification of patients in "total institutions", and other scholars, whose criticisms "pictured mental hospitals and orthodox psychiatry as repressive and mental illness as a social construct designed to justify the incarceration and control of individuals whose behavior was socially disruptive, economically unproductive, politically deviant, or morally objectionable" (McCandless 1996:2).

### **Deinstitutionalization**

Deinstitutionalization can be defined as "the shunning or avoidance of traditional institutional settings, particularly state mental hospitals, for chronically ill individuals, and the concurrent development of community-based alternatives for the care of this population" (Bachrach 1989:165) According to Bachrach (1989), three process are assumed by deinstitutionalization: depopulation of mental hospitals, deflection of patients to community-based service settings, and decentralization of responsibility for patient care from the hospital to multiple settings with fragmented authority.

The deinstitutionalization movement begun in the 1950's and 1960's, was supported by a "unique coalition of conservative and social reform ideologies" (Bachrach 1983:1). Community based care, the alternative thought to institutional care, was ideally both more humane and therapeutic and less costly. According with Kelly Johnson (1998b), who studied deinstitutionalization in Australia, this is a problematic process that involves a tension between two incompatible discourses: one of management and one of rights. The patients' rights definition focuses on the individual and his/her needs and rights, freedom, and autonomy. This perspective criticizes the isolation of the mentally ill from the society and

fighters for patients' right to be included into the community. "The foundation for deinstitutionalization is the assertion of a right to liberty or freedom which is assumed to be denied in large institutions" (Johnson 1998b:367). On the other hand, the management perspective of deinstitutionalization focuses on the management of people, resources and places, and not on civil rights. "It is argued that people who are regarded as 'different' or 'other' can now be managed in the community through the use of skills developed in psychology, medicine, and social work" (Johnson 1998b:377).

The United States was the first country to implement policies of deinstitutionalization. According to the historian Gerald Grobb (1991), a number of developments converged to reshape mental health policy in the second half of the twentieth Century. Experiences during World War II demonstrated the apparent efficacy of outpatient treatment for disturbed persons. A shift in psychiatric thinking toward psychoanalysis and recognition of the role of socio-environmental factors let psychiatrists start to consider the possible social nature of psychiatric illnesses, and started to advocate in community-based early prevention of psychiatric problems. As Grobb (1991) also states, the faith that psychiatry was able to identify the social and environmental factors affecting psychical health and the appearance of psychosocial and biological therapies (including psychotropic drugs) held out the promise of a more normal existence for individuals outside mental hospitals. Finally, an enhanced social welfare role of the federal government hastened the transition from an institutional based to a community-oriented policy. Community Mental Health Centers Act was passed by Congress and signed by President John F. Kennedy into law in 1963, and deinstitutionalization officially began, accompanied by federal money to fund care in community facilities (mostly private) through Aid to the Disabled and soon through Supplemental Security Income and Medicaid.

Other factors such as the cost of mental hospitalization versus its alternatives, accumulating literature documenting the detrimental effects of institutions on patients, anti-

psychiatric ideas about the “myth of mental illness,” and court decisions (such those mandating the “least restrictive alternative”) also were motivations for deinstitutionalization (Shadish et al 1989; Krieg 2001).

Depopulation of state mental hospitals in the United States was accomplished quickly. In 1955, 559,000 patients were interned in American state mental hospitals, and by 1981 the inpatient population decreased to 125,000. Many psychiatric hospitals closed, especially during the 1970's. As an example, thirteen mental hospitals were closed between 1970 and 1973), while others were downsized and partially closed (Bachrach 1989; Shadish et al 1989). But there was insufficient planning and funding for the second part of the process, the opening of community facilities. In other places, such as some parts of Italy, the beginnings of the process of deinstitutionalization also lacked a planned and well-funded alternative system of community mental health services (Scheper-Hughes and Lovell 1985).

During the 1970's post deinstitutionalization services in the US were recognized as unacceptable. The mental health system failed in providing treatment and care for discharged patients, but also for a new generation of “new chronics” who were never interned in state hospitals. The National Institute of Mental Health gave birth to the idea of Community Support System, which was implemented during the 1980's. It consisted on a complete set of community services such as case management, treatment, psychosocial rehabilitation, self-help, basic support (shelter, meals, health care), and advocacy for rights protection, including crisis intervention (Anthony 1993).

During the 1990's the civil rights discourse, always subservient to the needs of efficient and economical management (Johnson 1998b), gained in strength and a new approach to mental health appeared in the United States. “Consumer-based” views and a recovery-oriented approach that involved giving attention to subjective outcomes, understanding recovery as a personal process of changing one's attitudes, feelings and roles and acquiring self-determination and self-esteem (Anthony 1993) appeared, but unfortunately

it has not been fully implemented. In 1999, the United States Supreme Court issued a landmark decision in rights with the *Olmstead v. L.C.* case. The court ruled that unnecessary institutionalization (either in mental hospitals or in other institutions such as nursing homes) of persons with disabilities is a form of discrimination. However, the mandate of integration in the community has not been well implemented. The implementation of this decision favored individuals with developmental and psychical disabilities and not the mentally ill (Mathis 2001).

Beyond the differences between the rights-based intentions and the outcomes of deinstitutionalization, the process made a revolutionary change in the mental health care system previously centered in the mental Hospital, and this change was largely needed. In Argentina, as with the previous revolution created by the asylum and the “moral treatment” deinstitutionalization appeared with many decades of delay, in comparison with Europe and the United States. The *desmanicomialización* movement<sup>17</sup> and the ideas of antipsychiatry exist, as well as in other countries, since the sixties, but the particularities of Argentinean history and of Argentinean socioeconomic reality made it impossible to move towards hospital closures and community-based care. However, innovative programs planned and implemented from within the mental hospitals have appeared in the last decade, opposing resistance to the traditional psychiatry.

### **The State Mental Hospital in Argentina**

The health care system in Argentina is a mix of private and public medical institutions. Through a universal public health care system the poor are treated in public hospitals whether the rich are primarily treated in private medical clinics. The mental hospital (asylum or *manicomio*) had been, since the second half of the nineteenth century, the place for care of the poor mentally ill.

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<sup>17</sup> “*Desmanicomialización*” comes from *manicomio* (asylum) and is used in Latin America as “deinstitutionalization.”

During the last decades of the nineteenth century and the first decades of the twentieth century, the larger asylums of the country were built in Buenos Aires, Santa Fe, and Córdoba. The ideas behind the constructions of the public asylums were those positivist ideas of “progress and civilization” of the hygienist and alienist movements, the same that influenced the construction of “modern” asylums for the treatment of the “insane” in Europe and United States decades previously (Vezzetti 1985; Ingenieros 1920; Requiere 2000). These asylums are still opened as mental hospitals and housing thousands of poor mentally ill, but they are not “modern” places for the cure of madness, as it was thought in the past when psychiatry believed in the potentialities of the asylums for the “moral treatment” (Foucault 1999:236). The asylums never fitted the requirements of the ideals of order and government of the alienists; they were born with overcrowding and chronic insufficiency of resources as a norm, and the police, judges, and even physicians have never really stopped the old habit of using the asylum as a place of seclusion for people who are marginal and abandoned (Vezzetti 1985). But today even the moral and medical ideal sustaining the asylum (cure, reform, and recuperation of the working class of the nation) does not exist any longer. Nobody reclaims inpatients as manual workers. During Perón’s government of “social justice” in the 1940’s, proposals for reforming the system of mental health care were presented, but they remained ineffectual. Instead, psychiatric hospitals were reconstructed and enlarged. During the second half of the 1950’s a group of psychiatrists influenced by psychoanalysis began attempts to transform the mental health care system, with ideas of replacing the traditional asylums with day hospitals, therapeutic communities, and general hospital clinics (Ablard 2003). In 1957, the National Institute of Mental Health was created as well as the *cátedra* (professorship) of psychology in Buenos Aires University, and the first psychopathology service in a general Hospital, with the psychiatrist Mauricio Goldemberg<sup>18</sup>. But while in other countries the

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<sup>18</sup>Topía. *Psicoanálisis, Sociedad y Cultura*: “Seminario sobre el libro *“Las huellas de la memoria. Psicoanálisis*

condemnation of asylum-centered psychiatry gave rise to deinstitutionalization and community-based care policies, in Argentina the Military coup of March 24 1976 cut all intents of progressive psychiatric reform. As Ablard (2003) narrates it,

In April 1976, the military passed a law intended to facilitate the removal of government employees from their posts for ‘presumed or potential ideological disturbance.’ By July 1977 virtually every psychiatric and general hospital and public health centre that offered alternatives to the traditional asylum had suffered serious loss of personnel (Ablard 2003: 371).

Psychiatry remained asylum-centered and biologically oriented, and the custodial techniques were even reinforced (Ablard 2003). During the 1970s some changes were made in the health system, its decentralization being the most important of them, previously State administered and funded hospitals were transferred to the provinces (Hartfiel and Kuravsky 2002). With the return of democracy in 1983 the movement of progressive psychiatry slowly re-appeared, as well as a more interdisciplinary field of mental health. But the focus of most of these movements was not the dismantling of the asylum but its reform and humanization. Interaction with the community and rehabilitation of patients from inside the mental hospitals, were promoted, preparing the ground for a deeper transformation in mental health that would arrive later<sup>19</sup>.

Argentina is still in this stage, speeded up during the last few years with movements, isolated transformative actions, programs of psychosocially oriented rehabilitation, and even some new legislation. But programs remain scarce in budget and personnel and legislation is limited or unimplemented, and psychiatric public hospitals are still central to the mental health system. According to health professionals from Clovera Hospital, ninety nine percent

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*y Salud Mental en la Argentina. Tomo I (1957-1969)*” by E. Carpintero and A.Vaine, 2004: <http://www.topia.com.ar/articulos/805-hue-1erenc.htm>, consulted May 15, 2006. For a detailed account of Goldemberg’s service at the Lanús Hospital and the creation of a psychoanalytical and psychiatric tradition see Sergio Visakovsky (2002).

<sup>19</sup> Estucplan : “*Estado, Salud Mental y Trabajo. Relaciones entre flexibilidad laboral y salud mental de los trabajadores*” by J. Ahumada and M. Magrini, 2000: <http://www.estrucplan.com.ar/Articulos/verarticulo.asp?IDArticulo=540>, consulted May 15, 2006.

of patients are not voluntary but have been committed by a judge (around four or five percent by a penal judge and the rest by a civil judge).

During the 1990's the provinces of Río Negro and San Luis passed laws prohibiting the opening and functioning of *manicomios* (asylums). Regardless of the value of these measures for the population of those provinces, we have to take into account that these provinces have a very small population<sup>20</sup> and they did not have any large *manicomio* as in Buenos Aires province. In Río Negro, the only hospital interning psychiatric patients was a general hospital with psychiatric service, with around 40 beds and only 20 chronic inpatients<sup>21</sup>. A change in the mental health system, in order to be significant and representative of the country, has to include Buenos Aires province and City because in Argentina medical resources are largely concentrated there. They have together almost half of the nation's population (2,776,138 inhabitants in Buenos Aires city and 13,827,203 in the province<sup>22</sup>), and concentrate more than half of the medical establishments, almost 70 percent of the psychiatric beds available for internment, and five of the seven largest psychiatric hospitals in the country<sup>23</sup>.

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<sup>20</sup> 552,822 inhabitants Río Negro and 367,922 San Luis, according to the 2001 National Census INDEC <http://www.indec.mecon.gov.ar/>, consulted May 15, 2006.

<sup>21</sup> *La Borda, Cultura y Sociedad*: "Se Siquiatrizan los Conflictos Sociales" <http://www.labardarevista.com.ar/Barda01/tsesiqui.html>, consulted March 15, 2006.

<sup>22</sup> National Census 2001, INDEC. <http://www.indec.mecon.gov.ar/>, consulted May 15, 2006. For 2004, the Buenos Aires Health Ministry publishes 14.633.271 inhabitants for Buenos Aires province [http://www.ms.gba.gov.ar/autoridades/subsecretarias/planificacion/pdf/vitales\\_pdf/Hechos2004.pdf](http://www.ms.gba.gov.ar/autoridades/subsecretarias/planificacion/pdf/vitales_pdf/Hechos2004.pdf), consulted May 15, 2006.

<sup>23</sup> According to data of the National Health Ministry in 2000 (<http://www.deis.gov.ar/guia.htm>, see statistics: "establecimientos de salud," Consulted April 15, 2006), Buenos Aires Province has a total of 4,897 health establishment and Buenos Aires city 1,663. Santa Fe and Córdoba have 1,870 and 1,772 respectively, and the rest of the provinces had an average of 480 health establishments. Buenos Aires province has 9,849 psychiatric beds for interment, with 4,100 of those beds in three public psychiatric hospitals; and Buenos Aires city have 3,526 psychiatric beds, with 2,590 of them accumulated in two public psychiatric hospitals. With the exception of Santa Fé, Córdoba, and also Entre Ríos, which also have a large asylum each, the rest of the provinces have an average of 141 beds available for psychiatric internment, and some provinces do not have establishments for the interment of psychiatric patients at all.

In Buenos Aires City, Law 448<sup>24</sup> was sanctioned in 2001 and recently passed in 2005. It is a progressive legislation that contemplates the transformation of the hospital-centered model of mental health. It favors ambulatory treatments, rehabilitation and familiar, labor, and communitarian reinsertion; institutionalization only when ambulatory treatment is not possible, and the creation of communitarian mental health centers and structures such as outpatient clinics, day and night hospitals, domiciliary emergencies, mental health care in general hospitals, sheltered facilities of less than 20 beds, half-way houses, sheltered workshops, substitute families, and therapeutic farms. However, the required community resources for their deinstitutionalization were not fulfilled and psychiatric hospitals remain almost unchanged. In fact, the budget for mental health goes almost its totality to the neuropsychiatric hospitals (Barraco 2006). Through different notes appeared in newspapers and in the internet, we can see that there is a strong resistance to the new law from the professional associations of psychiatrists as well as most hospital employees<sup>25</sup>. As Barraco (2006) states, some professional associations and Unions are making difficult the development and implementation of the New mental health law; they reject, among other things, the interdisciplinary approach to mental health enunciated in the law, and they even have started judicial actions against some articles of the law. Meanwhile, the requirements of placing psychiatric beds in all general hospitals have not been fulfilled, nor are the psychiatric-psychological guards and mental health teams in every health center. There are neither human nor material resources available for day hospitals, half-way houses, and other

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<sup>24</sup>Psicomundo Argentina: "Ley de Salud Mental de la Ciudad de Buenos Aires"  
<http://www.psicomundo.com/argentina/leyes/ley.htm>, consulted May 15, 2006

<sup>25</sup> Asociación Argentina de Psiquiatras: "Reclamo de Instituciones Médicas por el Proyecto de Reglamentación de la Ley de Salud Mental" <http://www.aap.org.ar/ley-salud-mental/ley-sm.htm>;  
*Prensa Obrera*: "¿Una Ley Progresista?" <http://www.po.org.ar/po/po676/leyde2.htm>;  
*Página 12*: "Instituciones de Salud mental en la Ciudad de Buenos Aires. La ley de la Locura"  
<http://www.pagina12.com.ar/diario/psicologia/9-58464-2005-10-30.html>  
*Tribuna de Salud*: "No al cierre del Moyano"  
<http://tribunadesalud.com.ar/taxonomy/term/6?PHPSESSID=2187013e10ee5ace60bdb13347c5e7a4>  
All consulted May, 15 2006

devises needed according to the law. A new socio-political movement for *desmanicomialización* and institutional transformation was formed in order to demand the implementation of the law, but at the present no changes are observed.

Buenos Aires Province, where Egidio Clovera Hospital is located, is still regulated by mental health Law 8.388 of 1975, which is centered in the psychiatric hospital and does not mention deinstitutionalization. Nevertheless, isolated programs of *externación* of psychiatric patients from within psychiatric hospitals have come out as personal projects since the late 1980's. These projects or programs are not centered on closing the neuropsychiatric hospitals but trying to humanize them and to *externar* long-term patients, substituting the custodial aspects of institutions for a more psychosocial rehabilitative approach. The projects try to open the psychiatric hospitals to the community in order to give rise to solidarity actions and to decrease stigma. It could be seen as the first steps taken in order to create a public acceptance of people with psychiatric illnesses. Examples of these projects are a life radio run by patients and open to the community since 1991 in a hospital in Buenos Aires City, a Marathon and *correccaminata* (something in between running and walking) organized in Clovera Hospital since 1995 for people from inside and outside the Hospital, music festivals, carnivals, invitation of local bands or other artistic groups to play inside the hospital, as well as to show artistic work of patients outside the hospital, such as theater performances or photographic expositions.

Besides these projects, a special emphasis is put on the need of *externar* patients that would have the psychiatric discharge from the institution but remain there because they do not have where to go or because they do not have the *alta judicial* (judicial discharge). On one hand, the health minister and health professionals working in the mental health system complain about the barriers put by the judges for *externar* patients (around 90 % of psychiatric hospital patients in Buenos Aires province are interned by judicial order. "Today,

the mental health policy is made by a judge,” says the health minister<sup>26</sup>). On the other hand, the Justice, when civilian and (rarely) penal judges decided to approve the *externación* for some of the patients under its tutelage, deplores the dearth of community mental health services of the provincial health system. Therefore, the Justice has opened, through its “*Curaduría Oficial de Alienados*” (State guardianship of mentally ill), a half way house in 1988, a *casa de convivencia* for women in 1990, and a Day Center in 1998 for those ex-patients under its tutelage because of a trial for insanity<sup>27</sup>.

Some mental hospitals, besides the lack of support from the provincial Mental Health system, have opened a half way house or a day hospital too. The most important program from the provincial Health Ministry, unfortunately implemented in only one hospital, is PREA. PREA, *Programa de Rehabilitación y Externación Asistida* (Rehabilitation and Assisted *Externación* Program) for psychiatric patients, was approved by the health ministry in 1999. Its objectives are the rehabilitation, *externación*, and social reinsertion of deprived inpatients ready for *externación* through *casas de convivencia*. Patients have to continue a psychosocial and occupational therapy treatment while living in the houses, and they have to participate in a day center and recreational and artistic workshops. PREA gives special importance to the social value of work. According to some sociologists working in PREA, a patient who finds a role of worker leaves his role of sick person; working is seen as a way of acquiring autonomy, self-esteem, social relations, and having the possibility of making projects (Hartfield and Kuravsky 2002). “Social companies” (*empresas sociales*) and

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<sup>26</sup> Diario Hoy, May 19, 2006. “Casi el 90% de pacientes de neuropsiquiátricos están internados por orden judicial” <http://www.diariohoy.net/notas/verNoticia.phtml/html/229054/>, consulted May 19, 2006

<sup>27</sup> In Argentina people may be judge and declared *insana* (insane, demented) or *inabilitada* (incapacitated, disable). The Argentinean civil code differentiates “demented” persons, who are declared insane and have annulated their civil life (art.114), and “incapacitated” persons, who are not demented but have a psychiatric disorder, and who have restrained only some rights; they can vote, marry, etc. but they cannot decide about their patrimony (art.152). These persons have a *curador* (curator) in charged of their legal issues and proprieties and they may be interned in a psychiatric hospital against their will. [The word “Curator” comes from 14th century Latin, from *curare* “to care for” (Encarta World English Dictionary)]. The curator may be a member of their family or a judge. “*Curaduría Oficial de Alienados*” (State guardianship of mentally ill) is the justice office where a curator works.

cooperatives in which ex-patients, families, health workers and also unemployed people work producing and selling jam, conserves, or other things are being planned and timidly implemented in Río Negro, Buenos Aires, and other regions.

Around 50 women have been de-hospitalized through PREA in one of the psychiatric hospitals of Buenos Aires province. The Health Ministry sent health professionals to Clovera in 2001 in order to implement PREA there too, but it did not work, and there was resistance from hospital professionals who were already implementing similar programs designed by themselves, as we will see in the next chapter.

The issue of closing the psychiatric hospitals is debated today in Argentina with more strength than ever, because it is clear the country's large delay with respect to other countries where deinstitutionalization policies have been implemented more than forty years ago. But there is disagreement about the need to close the state asylums. After a decade of indiscriminate privatization of previously State-run services and companies, health workers fear that the State would take a step back in its responsibility as guarantor of the public health, if hospitals are closed. Health employees are concerned about their jobs, and psychiatrists name the problems of deinstitutionalization elsewhere (homelessness, abandonment of patients, privatization of mental care facilities, etc) as proof that it is complex and difficult to close the state mental hospitals. The still large unemployment rate of the country and the large marginal population nourish the controversial idea that those who are mentally ill are better cared for in an institution and not abandoned in the streets. A real transformation of the mental health care system should culminate with the closure of the *manicomios* and their replacement by other State public forms of assistance in the community, but to negate the value of the present projects and programs while expecting instead a radical deinstitutionalization is to negate the benefits that patients actually obtain from them, the personal involvement and work of well intentioned health professionals, and the reality of Argentina today.

## **Egidio Clovera Hospital**

Egidio Clovera Hospital is a public psychiatric hospital located in the province of Buenos Aires, Argentina, adjoining a small town seven miles far from the main city. The landscape corresponds to a region defined by Archenti and Ringuet (2000) as *region rural periurbana*, a zone that is not exactly a suburb because the territorial occupation is not as concentrated as in a suburb, but neither is it a rural area. There is a discontinuous succession of housing units together with small fields, deposits, farms, forage stores, construction materials deposits, etc. The few blocks next to the hospital, called “the town,” show more houses and shops; the houses are built of different quality of materials, and there are small and humble wood houses, houses under eternal construction, very old houses, or new brick and red tile roof ones. In general, it can be said that it corresponds to a lower-middle class and low-income community. The non professional staff positions at Clovera are the principal sources of job for the town. The hospital is an asylum for around 1400 long-term psychiatric inpatients interned in the “chronic” sector, but also offers psychiatric outpatient services and general clinic services to the “inside” and “outside community.”

As mentioned previously, Clovera Hospital was one of the first “hospitals for the insane” in the country, opened at the end of the Nineteen Century and administered during the first decades of the 20<sup>th</sup> Century under the ideas of the alienist and hygienist movements. Built as a large number of pavilions separated by parks and gardens, with open fields for farming and the implementation of “labor therapy” in agricultural colonies, the hospital was thought as a place for practicing the “moral treatment”, new at that the time, where patients had the freedom of walking and working in the grounds of the hospital. Today, the establishment still has the aspect of a small town, with internal streets and parks, but the advanced institution thought as a place for the cure of the “insane” does not exist any more. Clovera Hospital saw the arrival of democracy in 1983 with wards of hundred patients with only one nurse in charge. But assemblies, therapeutic community, and other progressive treatments appeared,

slowly downsizing the patient population from around 3,000 inpatients to around than 1,500 by the year 2000. Today, with less than 1,300 inpatients, the asylum still exists.

The establishment itself is old, in bad conditions, and there are no gardens but just fields of grass and ancient trees. It is not, however, a closed institution, according to the neighbors of the Hospital. A well-built relationship between Hospital and town exists, and many patients do not stay apart from this relationship. The town's Catholic church belongs to the Hospital and opens its doors to the outside and inside community for religious services. Neighbors are used to seeing and being with hospital patients who also walk the nearest streets. Some of them are known by everybody in the town. It is as if the Hospital walls were extended to include the town.

Neighbors –who are at the same time hospital employees - and their children enter the Hospital every day to take a short cut to their houses, play soccer in the Hospital courts, visit friends at work, participate in “rehabilitation” and “community integration” artistic classes, social events and other activities in which patients also are participants. As an employee of the hospital once told me, “I used to come to the hospital since I was a child. I used to come to hunt pigeons, to walk...” The town has integrated the patients to its environment. “The persons living in the hospital, the patients, are more from this town than many of us –told me a neighbor from the hospital- because they have been here for forty, even fifty years. There was a patient who worked around forty years at the church, from the year 49 to the 99. He was the man of confidence for the priest, and did a function in benefice of the community *intra and extrahospitalaria* (the community from inside –inpatients, employees, professionals- and from outside the Hospital).” Other opinions of hospital employees/neighbors are “we are used to *convivir* (live together) with the patients, it's normal for us.” “We were raised with them. That is why a patient is not a rare thing for us. When we go shopping we meet them, they follow you, you talk with them, they are in the street; they are part of this town.”

In this context, it is difficult to say that all patients are under the permanent gaze and control of the institution. As Gibson (2004) saw in a hospital in South Africa, there are numerous instances when patients become invisible instead of being under the surveillance of the medical or State gaze. At Clovera, patients even manage to escape some of the ward's control. Official rules are made flexible in the daily and informal life, and patients take part in the construction of this life, finding opportunities for work, making friends, having some income. Patients in Clovera have a position that shows that they are not homogeneous as traditional psychiatry always saw them. For those who daily interact with and make use of Clovera Hospital, this institution may be seen in a similar way as in McCandless's (1996) understanding of American asylums in the late nineteenth century. He says, agreeing with the historian Gerald Grob, that "asylums were not simply hospitals, as progressives such as Deutsch<sup>28</sup> claimed, nor were they essentially jails or reformatories as the revisionists argued. They were multipurpose institutions whose nature and function varied according to time, place, and circumstance" (1996:3).

### **Life Inside the Hospital**

After being admitted to the Emergency, going to the Crisis Attention Service, and transferred to the Acute or sub-Acute sector of the Hospital (places in which patients can stay for short to medium periods of time), a person who for medical, socio-economical, or judicial reasons can not be discharged is interned in a psychiatric ward at the rehabilitation sector (more realistically known as the "chronic" sector), and becomes a "patient", as everybody know them.

### **The Hospital Psychiatric Ward**

Most psychiatric chronic wards (*salas de crónicos*) at Clovera are similar, in their architectural and furniture aspects, to Goffman's (1962) descriptions of the 1950's institutions

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<sup>28</sup> Albert Deutsche, early twentieth century historian of insanity in America.

in the United States. A typical ward consists of a large dayroom-dinning room, the dormitories, the nurses' office, and the psychiatrist's consulting room. At the dinning room, called "*el comedor*," patients have to spend most part of the day. Those who are not "*bed patients*" (physically disabled or very old) can not stay in the dormitories during the day, and have to remain in "*el comedor*" or in the little fenced yard adjacent to it, called "*el corralito*" (the little corral). That yard usually has no plants or flowers at all, but only a small grass or soil area with a rope with hanging cloth, and a small gallery over a concrete floor, sometimes with plastic chairs. "*El comedor*" is a large rectangle with a very high ceiling with a small T.V. holding high in one extreme of the room and long cement tables and branches organized in a school-type line. There is also a limited kitchen in the other extreme, not for cooking but for washing the dishes. There are no armchairs or coffee tables, and patients watch TV from the cement tables and branches. There are no other entertainments such as bookshelves, pool tables, table games, etc. The dormitories are usually located in two wings, one in each side of one extreme of the dayroom-dinning room, and usually a locked door separates these two environments so patients can not go to the dormitories when they are not supposed to. The rule of remaining in the *comedor* instead of being allowed to stay in the dormitories is something that Celeste remembers about her life in the Z ward: "it was horrible, after you talked with the doctor and she made your head like this (makes a gesture with her hands on the sides of her head), and then the nurses sent you to the *comedor*, with all the other girls (*chicas*) there and too much noise (still gesturing with her hands in her head) and you just wanted to be alone but they sent you to the *comedor*" (Celeste July 2005).

The organization of the beds in the ward is typical of this kind of institutions, being one bed next to the other in both sides of the dormitories, with a small corridor in the middle and any kind of separation in between the beds. Privacy is not a characteristic of the ward. Most patients do not have a chest of drawers, commode, or wardrobe for their personal

belongings, and I have seen patients keeping their belongings under their beds or carrying them with them all the time for fear of thief.

Bathrooms and water closets are in the corridor between both dormitories, and there are two water closets in the back yard. Patients have days established for taking a bath, usually three times a week. They don't have personal appliances such as shampoo or deodorant, and nurses administer them because they are scarce. Patients eat with spoons, as no knives are allowed, and in most wards they cannot wash their clothes (which is washed at the hospital laundry) or cook their meals, which are sent from the hospital kitchen. Therefore, very few domestic and personal activities are performed by patients at the ward, except for those who manage to have privileges in exchange for their "collaboration."

In many wards<sup>29</sup> the only treatment done is psychopharmacological medication, and there is no psychosocial rehabilitation made by health professionals. A few non professional nurses try to do rehabilitation by their own means and as they understand it: celebrating patients' birthdays, going for a walk on the hospital grounds, and going out to social events, teaching art classes, etc. They engage in these activities without any accompaniment, support, or guidance from health professionals who may orientate them. Also, hospital workers such as administrative employees make use of the positive connotations of the term "rehabilitation" for justifying practices that include patients but serve other interests too, such as the Club del Trueque (exchange club), the Theater, the Cultural Centre, or the Farm.

Patients that I met at the Hospital often express their suffering living at the institution in relation to abandonment by their families (according to the Director of the Hospital, only 8% of the patients receive visits from their families. We should take into account that those families are mostly low-income and live far from the Hospital, since it is an institution that

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<sup>29</sup> I use the word "ward" instead of "unit" for three reasons: all social actors at the Hospital use these categories (so they are "native categories"); I do not want to call with a different and more politically correct name a reality that have not change; and the word "unit" refers in Argentina to another reality: it is a penitentiary's language.

receive patients from all the province and even farther); the bad provision of what they consider basic needs such as *yerba mate* and cigarettes (added to critiques of the quality of food and clothing), and fear about their future. After their *externación*, and from their new lives in the community, ex-patients retrospectively say that the worse things at the hospital wards were their lack of privacy, the lack of choice in options of domestic and personal activities (especially regarding time and frequency, such as eating, personal cleaning, cooking, going out, visiting friends/lovers or sleeping), and having to report their desires of doing any activity to the nurses and having to obey orders from nurses (such as going to the dining room while one wants to sleep, or cleaning this or that when one does not feel like doing that).

Long-term chronic patients, however, do not think that everything related to Clovera Hospital deserves being criticized. Even after leaving the Hospital, they criticize the life at the wards but are not really critics to the Hospital itself as an institution. This lack of criticism may be related to patients' process of institutionalism, but also to a conscientious use of the institution as a resource to confront the general scarcity/poverty of their lives. Goffman's (1962) description of the things a person loses when he or she enters a psychiatric hospital corresponds to a middle class American person, and does not coincide with the experience of patients from Clovera Hospital. The population of Clovera Hospital is mainly composed of poor, uneducated people, who were already marginal before entering the Hospital. People lose things when they enter Clovera Hospital; they lose their family, their few material possessions, their previous social identity. But some of them learn, together with hospital's low-employees, how to make use of the institution constructing it as a resource and as a domestic space<sup>30</sup>.

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Most of the ex-long term patients whose histories I narrate here had some kind of privileges and they made a productive use and construction of the space at the Hospital, even

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<sup>30</sup> For fuller discussion of these issues, see Dillon 2005

while suffering the same dehumanizing environment of the ward. Through their adaptation to the Hospital life they resisted some of the negative aspects of institutionalization.

### **Resistance to Institutionalism**

Goffman (1962) described how people lose the social identities they had previous to their entering a psychiatric hospital, and how within the institution their “role of patient” is the only recognized one. As McCourt Perring (1993) summarizes the process, “the entrance to the social role and status of patient involves a change in identity where the person is characterized in terms of her perceived symptoms” (1993: 2). Being a patient is being “something that functions badly and passively receives services to correct this disorder” (McCourt Perring 1993:77). Descriptions of patients’ lives at institutions show that they are regulated by a rational plan and they do not have contact with the outside world. The daily routine and the life inside the ward provoke long-term patients to become institutionalized. According to Wing and Brown (1970), institutionalism syndrome includes personal changes induced by prolonged residence in relatively closed communities with “poverty of the social environment,” and arbitrary and depersonalized routines and limits on the opportunities to practice normal social roles. As a result, institutionalized long-term patients are indifferent about leaving the Hospital and can be seen shambling, inactive, and apathetic.

According to Wing and Brown (1970) and Segal and Aviram (1978) the longer a patient remain interned, the less he would be willing to leave the hospital. The patient’s institutionalism is accompanied by a chronification of his illness, what erodes their functional capacities for daily life. However, patients are not homogeneous in institutions, and a more complete and complex view of this situation should be accompanied by the descriptions of the existence of long-term patients who resist the process of institutionalism and, in different degrees, achieve the aim of having a different identity and social identification.

Silvia Balzano (2005) observed that some long-term patients at a Buenos Aires province’s Hospital-Colony for people with mental disabilities (and psychiatric illness) resist

the social process of institutionalism, called by them “colonization” (undesired socialization or enculturation through which patients loose the normative habits of the outside world and become, in a way, des-humanized). Some patients at the colony studied by Balzano, those who are less disabled and deteriorated, compare themselves with other “colonized” patients and have a positive self valuation of their capabilities, what allows them to construct a positive identity. They re-elaborate the model of disability that label them from their intellectual capabilities and, instead, make one in which they emphasize their capability to function inside the Colony as autonomous persons. At the Clovera Hospital, in similar way, some long-term patients resist the institutionalism by engaging themselves in tasks that differentiate them from other “not lucid” patients, and construct relationships that enable them to have a social role, at least inside the Hospital. Of course, their position in the institutional hierarchy will always be that of the powerless compared to even the lowest employee, and they have to engage in domestic and even servile activities in order to obtain some “privileges,” but it is the only way they find, since there is no “consumer movement” in the Hospital or outside of it<sup>31</sup>.

I met most of the ex-patients who participated in my research when they were long-term hospital patients, but they were not “shambling, inactive, and apathetic” as other institutionalized ones. They participated in as many activities as they could find in the Hospital, constructed love and friendship relationships, and they were in charged of nurse-like duties that gave them a privileged position among other patients. Some of them, as well as other hospital patients, also developed friendships with hospital employees such as the theatre

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<sup>31</sup> According to Richard Weingarten, writing for the National Empowerment Center in the United States (<http://power2u.org>), of all the Latin American countries, only Brazil has a national grassroots consumer movement (“Brazil’s social movement to close mental asylums,” by Richard Weingarten <http://power2u.org/articles/international/brazil.html>, consulted May 15, 2006).

director or a retired nurse who works as a guard. Besides the bad quality and payment of the jobs they did at the hospital, they valorized them as part of their identity: “I’m the one who cuts the grass”, “I’m secretary at the sewing workshop”, “I am a waitress” were part of the patients’ self-presentation. Some of them found reasonably good activities and jobs to do, and they knew about the difficulty of doing the same in the outside world where unemployment is a critical situation. They saw themselves as different from other passive patients. This is how Rodrigo put it to me in a conversation we had in 2003: “We do not spend the day smoking and drinking mate. There are people who don’t have the mental capacity for work, or others who are lazy and don’t like to work. But the majority of people...I would say sixty percent of the hospitals [residents] work.”

### **Life Histories at Clovera Hospital**

Ayilin, Celeste, Rodrigo, María, and Pino are some of the now ex-patients that I knew when they were interned at Egidio Clovera Hospital. Their life there, described here from my observations and their accounts, was neither passive nor isolated. They resisted institutionalism engaging in work and other activities and constructed roles different from that of “patient.”

Ayilin spent 21 years interned at regular “chronic” wards of Clovera, where she entered when she was around 21 years-old. Her last ward, where she spent more than six years, was a ward for old ladies, and she was the only young woman. Ayilin always told me that she liked it there very much because she took care of the *viejitas* (old little ladies). She had an occupation as nurse’s assistant doing the cleaning and caring for other patients. Ayilin likes to say that she was thin then because she worked very much in the ward. “I had a tremendous agility, I woke at 5 AM, I cleaned the corridors and the bathrooms, I washed the patients, I extracted louses from the old patients, I helped the nurse, I took care of the *viejitas*.” Beyond the work at the ward, she participated of the hospital’s theater and she went every day to craft workshops at the Integration Council for disabled people in the city, where

she went traveling alone in the public bus every day. At the Hospital, she was always walking around, meeting people at the bus stops in the street, and accompanying people to the different hospital dependencies.

In 2003, Ayilin's doctor, in agreement with the Psychosocial Rehabilitation Center's (PSRC), decided to move her there. I saw her then, and although she liked living at the ward she recognized that her doctor was right saying that "she was wasting her life there." She knew that patients at the PSRC could be discharged, and she told her doctor that she could live alone. I remember feeling pity for her, thinking that it was not possible. But I was wrong and in less than two years Ayilin had left the PSRC and was living on her own in the community.

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Celeste was interned for more than 32 years at regular chronic wards before moving to the PSRC. She entered Clovera Hospital being around nineteen years old. She was discharged one or two times but she had difficulties in finding a job and she returned to the Hospital. She spent the majority of her life at Clovera, without any visit from her family, and when she narrates her history one can also see the history of the Hospital's changes over time. Celeste worked in different hospital units such as being secretary at the nursery (which later was transformed into the pigsty and then in the sewing workshop) and secretary at the sewing workshop. She received cigarettes and also some money, but she had to write notes directed to the Hospital's Director complaining about the usual delays in the pay. With the money, she would buy cigarettes for herself and for her "*compañeras*" (partners, friends). For eleven years she danced in the dancing workshop organized by nuns in the building where now is the Hospital's theater. Celeste lived most of the time at the same ward, where she had a privileged position because she "collaborated" with the nurses, "I even used to take the ampoules and filled the syringes!" She had several boyfriends at the Hospital, but she never wanted to have children as other patients did. She met Rodrigo, who was interned in another ward in the

opposite extreme of the Hospital, and they become *novios* (boyfriend and girlfriend). He had previously dated a friend of hers, another woman whom Rodrigo had met at the Hospital Theater and with whom he had a baby<sup>32</sup>. Celeste knew that they had broken up, and she started to send love letters to him through a common friend. They worked together at the Hospital farm, and during a barbecue organized at the farm Rodrigo talked to her and they become an item. This was in 1998 or 1999. Rodrigo bought a bicycle to go to visit her, since their wards were more almost a mile far from each other. She also used to visit him in his ward, taking a bag with cigarettes and *mate* to share with his ward's "*compañeros*." In 2003 Celeste was selected and evaluated to go to live at the PSRC and, knowing that Rodrigo was already there, she accepted.

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Rodrigo spent eighteen years at hospital wards before he was transferred to the PSRC. He was discharged twice but he returned to Clovera after *descompensarse* (de-compensation, a term used in psychiatry for meaning a loose of stability of symptoms and control of behavior). He spent eight years at one ward, two in another, and eight more in another ward, where he was "as if I were a nurse". During several years he was left in charge of the ward on Friday nights, when the nurse went out to dance. He gave the medication to the other patients, combed their hair and shaved them. In exchange for that "collaboration", he had privileges such as a private room, cigarettes and sometime some money. "We never had a bad time at the hospital," says Rodrigo talking for himself and for Celeste. Among other things, he worked at the laundry workshop, at the hospital farm, at the plastic bags workshop, and participated in the Hospital Theater. In 2001, when the PSRC opened, he went to live there. Only then did he re-establish some contact with his family.

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<sup>32</sup> She had the baby for three months, living interned in an especial part of the general part of Clovera Hospital, but after that time the baby was taken care in a hospital for orphan children, and later he was given in adoption. Rodrigo and the woman were never allowed to see the child.

María stayed 36 years at the same ward, where she was interned when she was seventeen years-old. Then, she spent two more years at the PSRC, from which she was *externada*. Her mother and sister always went to visit her, until her mother died. Her brothers and a younger sister never went. When her mother died, she only saw her sister, who lives in another city, occasionally. According to María, she had several possibilities to leave the Hospital and going to live with a family, but her sister had never approved that, and she is now sad about that because she always expected her sister to take her to live with her, but she never did it. Maria was very close to the *monjitas* (nuns) of the hospital, who were ward managers long time ago. She worked for sixteen years at the *costurero*, where hospital's cloth is sewn. She did not receive any salary because she did not have ID and therefore she could not be register for the *peculio*<sup>33</sup>, but she received cigarettes, *yerba mate*, and cloth. She worked selling inside the Hospital the cloth made at the sewing workshop, where she made friends with Marla, the teacher, and she also made friends with Nora, the hairdresser. At the Hospital, María started dating her present boyfriend, Sebastián, three years and a half ago. He was interned at a men chronic ward, and later both went to live at the PSRC.

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Pino was interned at the Hospital for twenty years. Only recently he has re-established contact with a cousin from Spain, but he never received any visit when he was at the Hospital. He had a long-term girlfriend there, and they were known by other patients as an established couple, but she died. He was always seen at the Hospital grounds and was very active. He created a radio program at the Hospital, doing interviews and writing about politics, football and other themes. He was close to the health professionals with progressive ideas that re-appeared with democracy in the 1980's, and was linked to the Pre-Discharge House and the *externación* service since its beginnings. He was friend of a group of patients called "the

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<sup>33</sup> The "*peculio*" is a small amount of money that the provincial Health Ministry gives to those inpatients who work at the hospital. It is usually administered by nurses or doctors.

walker poets,” who wrote poetry and later went selling a book that the Hospital made with it. Pino worked as seller of the plastic bags workshop since its creation around twenty years ago. He went out from the Hospital to visit his “clients” in several near towns, and he received a small salary for that job. He and other patients once went on strike because the pay was, as usual, delayed.

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When they were selected to move from their wards to the new Psychosocial Rehabilitation Center (PSRC) Ayilin, Celeste, Rodrigo, and Pino as well as other patients, found the opportunity to leave the Hospital and make a new project of life in the outside world. This possibility was unthinkable even a few years ago, when they were long-term chronic patients without family, without resources, and were condemn to stay excluded from society because they did not have anywhere to go or a way to sustain themselves. The new *externación* programs of the Hospital, especially the PSRC and a recent housing option called *casas de convivencia*, and the appearance or effective implementation of some governmental income-maintenance programs, made possible the *externación* to the community of these especial long-term psychiatric patients who resisted the worst aspects of institutionalism. The following chapter describes the *externación* programs of Egidio Clovera and the few income-maintenance programs existing in Buenos Aires Province and used by ex-patients as important tools in their *externación*.

## **Chapter 2**

### **New Programs From Within the Hospital, an Opportunity for Moving Out**

#### **Where and How to Move Out From Clovera?**

Egidio Clovera Hospital, as the other psychiatric hospitals of the country, received the arrival of Democracy in 1983 with the image of a backward and overcrowd asylum. The few attempts beginning from the late 1950's to the early 1970's to transform the mental health system and introduce rehabilitation and psychoanalysis (Ablard 2003) had led, during the military coup, to the return of the long-term isolation and segregation of people in institutions and to the hegemony of the biological model of psychiatry. Looking at the material conditions of the Hospital today, nothing seems to have changed, but the number of inpatient population has been lowered considerably and professionals have adopted new approaches.

Many people interned in Clovera have the possibility of having a medical discharge, but for different reasons they could not leave the institution and remained interned. Celeste says that “the problem is that relatives do not accept, the problem is in the families.” “They pester with the family, but the truth is that the family doesn't want anything to do with them,” says Alicia. The problem of not having any monetary income to live outside is also expressed for patients at the Center. None of the ex-patients whose histories I describe here count with their families for going to live with them or for monetary assistance. They may have no contact with relatives after long years of hospitalization, as Mariano recognizes from his own experience: “the family doesn't exist, forget it. Most people from the hospital don't have a family.” Daniel agrees with this fact, saying that “your family detaches from you, they (relatives) don't accept you any more; they don't love you any more. There is nothing you can do.” Ex-patients may have some contact with relatives but can not expect help from them or may not want to be a burden on them. Others, such as Rodrigo and Celeste, just want to have a regular relation as a father/mother of young sons, aunt/uncle, sister/brother, grandfather/mother, or son of an elderly father. They do not accept the position of children to

be taken care of by others. If they leave the Hospital they want to recover a regular role in their families. The first thing Rodrigo and Celeste told me about their trip to Rodrigo's daughter's house for Christmas was that they spent a lot of money buying things for the children. Roberto describes her little granddaughter asking him "grandpa, can you give me a coin?" and his answer: "ask granny Celeste, she will give it to you." He incorporated Celeste to the lives of his grandsons and at the same time he made her (who never had children) a grandmother. This desire to establish "normal" relationships and not that of dependants have been pointed out by Wilton (2004) in his study of the negative influence of poverty in the recovery of people with serious mental illness in Canada. He says that the lack of resources influences negatively the recuperation of family relations. The inability to afford gifts is an example of that negative influence of poverty in social relationships. "I can't even buy my grandchildren things for Christmas or anything like that. You just send them a lousy card. You feel torn apart" (Wilton 2004:33).

A relative's house, therefore, is not an option for most long-term psychiatric patients in order to leave the Hospital. Nor is their translation to a nursing home or other institutional setting, because there are no arrangements for the transfer of patients to these kinds of facilities in Argentina. However, since the late 1980's some professionals, most of who have been working at Clovera for many years, could work on the idea of doing rehabilitation and helping long-term psychiatric patients *externarse* from the Hospital. They searched for subsidies and housing possibilities and started to develop personal projects to be applied from within Egidio Clovera. They did this before any sign of change in government or hospital policy appeared in relation to a mental health system dominated by the centralization in the psychiatric hospital. Some projects took time in being implemented; others are still waiting for institutional and Ministerial support.

In the early 1990's Clovera Hospital had more than 2000 in-patients; in 2003, when I did my first fieldwork at the institution, there were 1450, and by 2005, when I started the

present research, the inpatient population was of less than 1200. The reduction in number of in-patients is related to different factors, including the death of elder patients. “In my ward we are 60 women. We were much more before, but a lot of ancients die” told me Ayilin when I met her in 2002. But also the Hospital (its management) has allowed and, in some degree, supported professionals implementing their personal projects with a psychosocial rehabilitative approach that, even though it is non homogeneous, is directed to the avoidance of re-internments and the discharge of in-patients. However, the whole Hospital is not oriented by those programs. They are small spots of light in what is still an institution for the unwilling internment of persons. The programs are isolated, not well supported, disarticulated, vulnerable, and limited; but they allow Ayilin, María, Mariano, Ester, Pino, Celeste, Rodrigo, Pedro, Daniel, Sofía, Dolores, and others to know a new life after years and years of being inside.

### **The Pre-Discharge Program**

In 1987 a psychiatrist opened a small ward outside Clovera, with the idea of doing rehabilitation and putting patients in contact with the community. The place was an old two-story house located in the center of the city, around six or seven miles from the Hospital and surrounded by residence buildings, houses, and small shops such as grocery stores, vegetable stores, laundries, barber’s shop, etc. In 1989 Patricia started working at the house, one of the first psychiatrists from the Hospital working in the discharge, following-up and communitarian reinsertion of patients. She says that for the first year the house was maintained by Catholic women, and it was just another ward of Clovera; fifteen patients lived there with the same habits of the wards and there were no workshops functioning, even though the house had donated sewing and shoe making machines. After a period of stagnation and low development of the project the house was slowly transformed into the present Pre-Discharge House (P-DH). They found a legal way of running the first workshops through the Cooperation Association of the Hospital, which managed the money and salaries. In 1989

they made an agreement with the Labor Formation Center<sup>34</sup> and while the CFL provided the teachers for the workshops the P-DH provided the building and the machines. The productive workshops (bicycle fixing, sewing, cooking, plastic bags, leather work, shoe making, etc.) were for the patients living at the house there and also for other patients who came from the hospital wards during the day. In 1994 they began to run the workshops through a Foundation (a non-profit corporation) and they did not use the Cooperation Association of the Hospital any more.

Pino, who has participated for many years in the workshops at the Pre-Discharge House, told me about the different kinds offered: notebook-making, serigraphy, cleaning clothes, plastic bags, and hand weaving. When I was doing my fieldwork, a sales point for those products was organized by two students of occupational therapy and some patients and ex-patients from the Hospital. It was set three times a week at the hall of the P-DH, with a big sign at the door. Pino was the principal person in charge of the sales, writing each sale in a notebook. When I asked him if he was working there for money, he said: "I want to help to organize this a little bit; I want to contribute to the workshops. They will give me something, sure." Knowing about this activity from Pino, Pedro also went to ask for a job as a seller, and he started working with other patients selling products in the neighborhood. The money is to buy more materials for the workshops, and sellers receive a small percentage of each sale.

According to the psychiatrist Patricia and to Mónica, a social worker from the P-DH, they started having problems of lack of space at the Pre-Discharge House. In addition, the budget for nurses was cut, and the staff got tired of dealing with a housing, treatment, and working facility all in the same small space. As Patricia put it, "It was a chaos; there was no doctor for the guard and only one nurse during the night. This place was a Day Hospital and a Night Hospital at the same time, with everything mixed: workshops, dinning room, bed

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<sup>34</sup>The CFL is located inside the Clovera Hospital but belongs to the Education Ministry; it is dedicated to vocational rehabilitation.

rooms, consulting rooms...and also there was a reduction in the assigned personnel.” The number of beds was decreasing and since 2001 no more patients have been living in the house.

The P-DH belongs, since 2000, to the then created “*Externación Service*” answering directly to the General Director of Clovera. It is the only program designed to work for the *externación* and communitarian reinsertion of patients functioning outside the Hospital. It focuses especially in the following-up of ex-patients, especially to the long-term hospital patients with psychosis, when they are living in the community. The P-DH staff follows a principle of working for ex-patients’ autonomy and independence, and regarding their link with their families, staff help ex-patients to re-establish contact with their families while encouraging them to remain independent from them. Answering a question about changes in family attitudes in a newspaper interview, Patricia said that “what has changed is the approach in this sense. Formerly, the family was asked to take care of the patient; today we try to have the patient achieve autonomy and we propose the families to accompany this process” (El Día, 15 Agosto 2004, my translation).

Presently the house works 12 hours a day, from 8:00AM to 8:00PM, and offers productive workshops, meals, and psychological and psychiatric treatment to around 70 ex-patients and patients (fewer) from Egidio Clovera Hospital. Since 1990 the P-DH is in charge of the administration and supervision of the *casas de convivencia*, a housing program planned by professionals of the P-DH for the *externación* of long-term psychiatric in-patients to the community.

### **The Casas de Convivencia**

A *casa de convivencia* is a regular house or apartment in any neighborhood where three or four ex-patients *externados* from a psychiatric hospital temporarily live (they can have a definitive or a weekly renovated discharge). They are the only supervised housing options for ex-patients from Clovera Hospital to live in the community. The supervision for

these houses comes from the public psychiatric hospital itself and no from any charity, volunteer, or for-profit organization -no private mental health care have been developed following patient's *externación*, as it happened in other countries (Shadish, Lurigio and Lewis 1989) - and this supervision is lax, just once a month or every two weeks, because the houses or apartments are not staffed. A *casa de convivencia* is close to the function of a *half way house* in the sense of being "a temporary-transitional facility for people released from the mental hospital who are not able to live independently in the community", a facility that offers "the help needed to 'bridge the gap' between hospital and community" (Segal and Aviram 1978: 79). But the meaning of this help and the causes of not being able to live independently are different in a *casa de convivencia*. Most ex-patients in a *casa de convivencia* cannot live independently because of income shortage, and the *casas de convivencia* are basically the only free option for ex-patients to live outside the Hospital when they do not have a subsidy or job for renting an apartment/house. There, ex-patients receive the support of their *compañeros* (partners) living in the house more than the support of the staff that only visits the house periodically (differently, half way houses are staffed).

The word "convivencia" implies the idea of living together and sharing domestic duties but also supporting each other and complementing the work and abilities of one with those of the other. It is the word commonly used by couples living together (but paradoxically the houses are not mixed by gender and are for three or four persons, not a couple). A *casa de convivencia* is not just a "group" house, where everyone is expected to do and to be the same, but a place where each person has its especial place. It is not a half way house either, since people living there have their medical complete or weekly-renovated discharge, and they live alone. The owner of the house has no responsibility for the ex-patients living there. There is no formal plan for the organization of life in the houses either, and ex-patients there have the option of organizing themselves as they want for the domestic, social, and labor activities.

The rent of the house and all its expenses is paid by the Hospital, except in rare occasions when a patient owns the house and shares it with other “*compañeros*” (partners). The idea is to offer transitional housing for those patients who are in conditions of being medically and judicially discharged from the Hospital but who have no place to go (no house, no family disposed to receive them) or monetary resources for moving out by themselves. One of the requirements for living at a *casa de convivencia* is to be under psychological and psychiatric treatment, but the house itself is not a therapeutic facility (as the PsychoSocial Rehabilitation Center is) or a shelter care one, it is a housing facility closer to a “satellite housing” (apartments subsidized by shelter care facilities in the United States where people live in a more “high expectation environment” for social integration (Segal and Aviram 1978:84). The ex-patients can live in *casas de convivencia* for an undetermined period of time, but the idea is that they have to develop a personal project of independence and moving out from the house when they find the means of living by themselves. It has occurred for example when a person finds a job or receives a social benefit that allows them to rent something by himself, or when he knows a person and goes to live with her/him.

Therefore, a *casa de convivencia* is not a place for living for life; residents are supposed to give their place to other *externados* some day. The *casas de convivencia* are not mixed. The Pre-Discharge professionals in charge of the houses states that mixed houses would be a mess with couples fighting and leaving the house, and it would be difficult to find a new couple for the house. In addition, they say, living together as a couple is a personal project that ex-patients have to construct by themselves; they have to find the way to move out to live together.

P-DH took the idea of the *casas de convivencia* from one opened by “*Curaduría Ofical de Alienados*” (State guardianship of mentally ill) in 1990. *Curaduría* (an office from the provincial Justice) developed some devices in the community for their represented psychiatric patients (a half way house for women, a day center, and three or four *casas de*

*convivencias*). According to Mara, a professional worker from *Curaduría*, they developed these devices in the community because the Provincial Health Ministry was doing nothing to promote patients' discharge and integration in the community. The present devices in the community of both systems (the health system and the judicial one) work in parallel and completely independently, with no articulation between them, even though some patients and ex-patients represented by *Curaduria* are ex-Clovera patients.

The first house opened in 1990 as a *casa de convivencia* by Clovera Hospital (through the P-DH) was own by a patient and with his agreement he went to live there with other two patients. The Housing Institute donated two other houses and Pre-Discharge opened them as *casas de convivencia*. After that, the inheritors of a patient who die donated the house to the Hospital for use as a *casa de convivencia*. Unfortunately one of the houses from the Housing Institute was lost (the Health Ministry reclaimed the house) and the other was occupied by squatters. Only recently it has been recovered. The Hospital has been renting more houses since, which are now about nine. María, Mercedes. And Sofía are living in one of these houses, ad Pino, Jorge, Pedro, and Mariano in another one (Mariano have recently move with Ester to an independently rented apartment). A problem related to the *casas de convivencia* is that the Hospital does not have much choice of houses to rent because people do not want to rent their houses to the Hospital. I asked Patricia and Mónica whether this rejection was because of the patients, but they said that it is because of the Hospital. Since it is a public institution, always with budget problems, they do not trust that they will be paid, and in case of accepting to rent the house they charge inflated prices.

Some years ago Pre-Discharge experimented with the substitute-family idea. "Never again!" told me Patricia. From hundred of families inscribed for the program almost anyone was in good conditions for housing ex-patients. Everybody wanted the money (\$300 -100 dollars- for each patient) but offered bad living conditions. Finally they chose a family that had two houses, one next to the other, and housed four women in one of the houses. But it did

not work and there were serious conflicts between the women, problems increased by the family that did not help in creating harmony at all. Two of the women got *descompensadas* (unstable in the control of their symptomatology) and were re-admitted in the Hospital, and the other two were sent to a *casa de convivencia* rented for them.

In 2000 PREA<sup>35</sup> appeared, which legally recognized the *casas de convivencia* for the discharge of patients. But this official recognition was not followed by a budget assignment for renting the houses. “*There is no budget from the health Ministry for that. Each hospital has to arrange things as it can.*” The only thing received from the PREA was a training taught by people from the Health Ministry. According to Patricia, a psychiatrist from the *Externación* Service, these people “had no idea or experience,” and the Service decided not to participate. Patricia thinks that “it is good that there is a legal frame for doing the program (of *casas de convivencia*), it is good that the program (PREA) exists, but it was only a political maneuver without real support, without a budget specified for the *casas de convivencia*. It sounds very well, as a revolution in mental health, but without budgeting it is impossible”. The Hospital pays the *casas de convivencia* using funds not originally oriented to that function.

### **The Day Hospital**

In 1995, Nora, a psychologist with many years working at the Hospital, opened a new program with the support of the Direction of the Hospital, implementing her project of a Day Hospital. This Day Hospital, as the Pre-Discharge house, depends from the *Externación* Service, but it is located inside Clovera Hospital and run mostly by volunteer students and young professionals. It offers a six to eight month treatment of individual and group therapy and daily workshops to ex-patients, and it is oriented principally to the maintenance of ex-patients in the community, avoiding re-internments. None of the ex-patients followed in my study participate of the Day Hospital, which is more oriented to young people who have been

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<sup>35</sup> See chapter 1

hospitalized several times for short periods, and most of whom live with their families. The Day Hospital is not intended for long-term “chronic” patients. But I described it because it has succeeded in maintaining people out of the hospital wards and helping to lower the in-patient population, and it has the functions that many community-based facilities have in the deinstitutionalization process in other countries. The difference, of course, is that this Day Hospital is not in the community but inside the psychiatric Hospital.

Even though the Day Hospital is not in the community, the staff do not really identify themselves and the project with the Hospital. “*It is not a project from the Hospital*”, says Nora, and explains how she thought about the project. “I was working in the SAC (Crisis Attention Service)<sup>36</sup> and I noticed that 50% of the admissions were re-admissions; they were people re-entering the Hospital for second, third, 10<sup>th</sup> or 15<sup>th</sup> time! The amount of re-internments called my attention.” Nora says that the main reason for these re-internments is the abandonment of the psychological and psychopharmacological treatments, because of a lack of following up and support.

She made an agreement with the psychology faculty of the University and a professor accepted to work with her and to teach a course of “community medicine” to volunteers and some hospital staff. Nora presented a project for a Day Hospital to the Director of the Hospital and he gave them a small building that was being used by rehabilitative nurses for workshops with chronic patients. “The original idea was to open the Day Hospital outside Clovera; but we were never allowed to go out.”

At the building there was no doctor or psychologist in charge of the workshops, which were about domestic and behavioral habits. Nora was designed by the Director to teach and supervise these nurses, who at the beginning were not very happy. She wanted to work with ex-patients living outside the Hospital but at risk of being re-interned, and the nurses were

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<sup>36</sup> Crisis Attention Service (SAC) is where every new patient is received at Acute Sub-Direction of the Hospital and from where patients are transferred, in case they need it, to the Acute, Sub-acute, or chronic sectors.

working only with chronic in-patients from the wards. During the first year (1995) there was only Nora and the nurses, who posed a strong resistance to her project. But in 1996 a group of students and scholars from the Forensic Psychology cathedra from the University come to work with her (as a volunteer job).

The objectives of the Day Hospital, according to Nora, are centered not only in the patient but also his family and his community. The staff visits the neighborhoods and homes where people attended at the Day Hospital live, encourage their participation and socialization, and give support to the families. Today, the Day Hospital works from Monday to Friday from 8:00AM to 4:00PM, and its structure consists in four areas: a technical team that offers group and individual therapy; the workshops; an area of communitarian and family attention; and a new area for research. One of the aims of the Day Center is that people make their own groups in their communities so some day soon they can stop going to the Day Hospital workshops because they would have another group where to participate. The communitarian and family attention worker try to encourage people to make contact with social institutions in their neighborhoods such as libraries, clubs, center for the retired, or choirs, and they encourage people to attend expositions, museums, theater, etc., since in the main city there are many free activities like that.

Nora says that “We have no budget, no supplies; this project is sustained by people who want to learn, volunteers.” Each workshop has a volunteer coordinator and three workshop-workers: students or new psychologists, social workers or sociologists doing internships. The functioning of the Day Hospital is not very well regulated because they sent a proposal regulation document to the Health Minister but they have not received any answer. Two years ago the Day Hospital was moved to a bigger building inside the Hospital, (an old rectangular building used from 1927 to 2001 as a ward and then abandoned and used for two years as a cultural center and Area of Social and Institutional Communication. This place is one of the few at Clovera offering alternatives to the old psychiatric hospital structure, and

that is why other progressive projects designed by professionals or volunteers find a welcome environment at the Day Hospital. A mime workshop, a photography workshop, or a Parkinson workshop has been developed in addition to the Day Hospital activities. The Parkinson project, for example, was designed by a neurologist from the Hospital and attracts people from outside the institution suffering from Parkinson's disease who go once a week to the Day Hospital and spend the entire day doing art, dance, tai-chi classes, and socializing and having their meals with the other participants of the Day Hospital. Even though the environment of the psychiatric hospital and the poor conditions of the Day Hospital's building are not the best for the rehabilitative work, all the activities, meals, therapy, etc. are free and it is a unique option for deprived people (in fact, the private sphere has not a better scene, and non-economically deprived people constantly ask for the Parkinson project too). "This is a key aspect of the Day Hospital: being a place of reference, a place where to go knowing that you will not be interned," says Nora.

Mirta, a woman that I met at the bus stop, takes two buses of around half hour each to attend the Day Hospital. She lives with her two brothers, her sister in law and a nephew in a house inherited from her father. Mirta had been interned in the Acute Sector of Egidio Clovera several times, most recently for six months. "Now I can talk with you, you can see; I couldn't have a conversation with anyone before," told me when I met her at the bus stop. "once a month they came to my house from the Day Hospital to see how I'm doing, how is the family. My brother told them how well I am, how different, and I was so happy hearing my brother saying such nice things about me".

### **The Psychosocial Rehabilitation Center**

In September 2001 the psychiatrists Alicia and Laura and the psychologists Julieta and Mariana opened a Psychosocial Rehabilitation Center (PSRC) that was a project presented years before by the two psychiatrists to the Direction of the Hospital. This Center is located inside Clovera Hospital in the building of an old closed ward, and houses a small group of

long-term female and male psychiatric patients evaluated and selected from the chronic wards for being rehabilitated and discharged to the community. In some way, this function was supposed to be offered by the Pre-Discharge House when they had patients living there. All the ex-patients participating in this study have passed through this Center. Most of them, different from those participating of the Day Hospital, are very long-term in-patients and do not have a family to go to live with. The Center, in agreement with the Pre-Discharge House, discharges some of its patients to the *casas de convivencia*, in groups of three or four (such as Mariano, Pino, Pedro and Daniel, and María, Mercedes, and Sofía). While P-DH does the weekly supervision of the houses, the PSRC is in charge of the following of the treatments (psychopharmacological, psychological, and psychiatric) of its patients living there. Others go to live alone in *pensiones*<sup>37</sup> (such as Ayilin), and still others, living the institution as a couple, independently rent an apartment or a small house (Celeste and Rodrigo, and later Mariano and Ester). These housing options do not depend on the Hospital as the *Casas de convivencia*, and Pre-Discharge staff does not supervise them. However, doctors and nurses visit their patients from time to time. They know the place where ex-patients live, and P-DH staff goes to *pensions* to check if everything is all right when they know about a problem or they see a person in need of something.

Because of its importance in allowing the ex-patients of this study to leave the Hospital and because it is where I did more fieldwork, I will describe in deep the PSRC in the next chapter.

### **Social Welfare Monetary Assistance Available for Ex-Patients**

The possibility of *externación*, especially to the *pensiones* and independently rented apartments, could not be achieved without some kind of public welfare subsidies, pensions, or

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<sup>37</sup> A *pensión* is an old large house with several rooms in a city owned by a single person who rents them for a small amount of money to a person, usually poor retired people or people receiving a pension for oldness, people with precarious employments or living of odd jobs, lower class students coming to the city to study, etc. They usually share a common bathroom and kitchen. In La Plata city pensions are about \$150, more or less depending on the quality, compared to \$400 of a one-bed apartment.

social plans for the ex-patients who do not have resources at the moment of leaving the Hospital. The situation is not optimistic, but it is better than a few years before when the possibility for patients of obtaining some subsidiary money for leaving the Hospital was non-existent.

One of the first program used to allow ex-patients and those patients close to their *externación* to have some monetary income was “*el plan*” (the plan), small monthly stipend paid by the Province government to unemployed people in exchange of part time jobs. Different kinds of these “plans” appeared during 1990’s in the nation and especially in Buenos Aires Province as a palliative for the high unemployment and economical crisis. When Celeste, Rodrigo, Ayilin, Ester, and others were living at the PSRC they had the “plan” “*Barrios bonaerenses*” (neighborhoods of Buenos Aires) or the “plan” “*Jefas y jefes de hogar*” (female and male heads of household), and they were *externados* holding these “plans.” None of these plans were originally designed for the mentally ill, and even less for purpose of the discharge of patients from hospitals<sup>38</sup>. But, since the distribution and administration of the plans have been unclear and surrounded by corruption, the professionals of the hospital got some of them for the patients. “The social plans are phony, that is why patients can lose them any time, but is the only thing we have” told me Alicia, from the PSRC.

A “*pensión nacional por invalidéz*” (national pension for disability, Law 18.910) from the National Human Development Ministry exists, legislated in 1997, for any kind of invalid

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<sup>38</sup> Originally, during the 1990’s the program “*Barrios Bonaerenses*” was a social plan from the government oriented to occupational training and labor qualification of unemployed household chiefs in conditions of social vulnerability, who received a small monthly stipend (a subsidy from \$120 to 200 Argentinean pesos [40-70 dollars]) in exchange for their part-time work in productive projects in ONGs in the Province. (Ministerio de Desarrollo Humano, Provincia de Buenos Aires: “Sola y Cafiero anunciaron pagos extraordinarios para beneficiarios de planes sociales” [http://www.mdhyt.gba.gov.ar/prensa/gacetilla/091204\\_02.htm](http://www.mdhyt.gba.gov.ar/prensa/gacetilla/091204_02.htm), consulted May 15, 2006). These criteria were changing over the time and also several irregularities have been denounced, such as subsidies paid to deceased people, or people getting this subsidy and other stipends or salaries at the same time. Patients at the hospital did jobs such as bathroom cleaning (Ester) or picking-of cardboard (Rodrigo, earning \$120) for sale by the Cooperative Association. The plan “*jefas y jefes de hogar*” is a similar plan but organized by the national government. Celeste had it at the Hospital, earning \$150.

person. “The traditional difficulty for obtaining it seems to be decreased now. This pension gives \$285 Argentinean pesos (less than 100 dollars) per month to people with less than 69 years of age with a permanent disability for working, whether a total or partial disability, that is, of 76% or more. For applying to this pension people must not have any other income, pension, retirement, salary, or goods or other material resources, and he/she must not have any relative obligated to sustain him/her<sup>39</sup> .

Most ex-patients from the Egidio Clovera fit in the requirements for this pension (even though I would say that they are not incapable of working, but doctors have to say that for them to get the pension). Doctors, psychologists, and social workers at the P-DH, the PSRC, the Day Hospital, and other dependences of the institution are trying to make ex-patients get this pension. This is neither easy nor quick, because many patients do not have their DNI (national identity document) and therefore other proceedings are required first. When I visited Ayilin in January 2006 she was waiting the visit of a social worker from the government who had to determine if she fit in the requirements for the pension. She had a letter written to her by her doctor pointing out all the things she may have to show to the social worker. Ex-patients work as much as their health workers doing proceedings for their pension. Celeste and Rodrigo had just got the national pension when I saw them in January 2006. Different from the social plans that are not officially recognized for them and are always possible of revocation, ex-patients know that the national pension is for life.

Since 1984 the Supreme Court of Justice gives a specific benefit for *externación* (Law 10.315 “*externación de enfermos mentales*” (discharge of the mentally ill) to the ex-patients represented by a curator from State Guardianship of mentally ill (*Curduría Oficial de Alienados*) who cannot be discharged from provincial psychiatric hospitals because they have no relatives who receive them or because their families have no monetary resources for doing

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<sup>39</sup> Ministerio de Desarrollo Social de la Nación. “Pensiones Asistenciales” <http://www.desarrollosocial.gov.ar/pensiones/pensiones8.asp> , consulted March 22, 2006)

that. According to Mara, a professional from *Curaduría*, this subsidy may be given also to people classified as *asistidos* (“assisted, who are unstable in their psychic functions but who are not demented) who have a curator and are not interned but need the money to remain out of hospitals. This subsidy was suspended during several years but it is working now. It is equivalent to the official minimum retirement, and it is temporal (six month with a possibility of renewal), until the ex-patient find a job. This subsidy is part of different devices implemented by the “*Curaduría oficial de alienados* in Buenos Aires Province for the *externación* of some of its represented patients, such as a day center, a half way house, a few *casas de convivencia* and pensions. Daniel receives this subsidy and he also participates of a electricity workshop at the Day Center of *Curaduría*.

Most recently, in May 2005, an agreement of collaboration between the Provincial Health Ministry and the Provincial Ministry of Human Development announced the creation of a new subsidy: the program “*vuelta a casa*” (“homecoming”), which gives \$280 a month specifically for the discharge and social reinsertion of psychiatric patients from mental hospitals. Rodrigo and Celeste have this subsidy now, in addition to the national pension.

Other few plans and benefits exist at a local, provincial, and national level for people with disabilities, especially children. Even though the mentally ill does are no commonly contemplated here (different from people with mental disabilities), professionals make them fit in this category when it is convenient. “For us, the patients of the hospital sometimes are considered disabled, sometimes not, it depends on the strategy for obtaining resources”, told me a professional from the P-DH. They have to do a hunting-like work for finding and obtaining benefits for the ex-patients. For example, Ayilin and Mariano participate of the Municipal Council for the Handicapped which has a center in the city where they go to labor qualification workshops (Mariano), artistic workshops (Ayilin), and entertainments.

The stipends of \$120 or \$150 Argentinean pesos from a social plan, or \$280 from a pension or subsidy, amounts to very little money in Argentina. Renting a one-bedroom

apartment in the closest city from the Hospital costs not less than \$400 a month; a kilogram of bread costs around \$ 3 pesos; a liter of milk is \$1,80, and a pair of shoes is no less than \$30 or \$40. Ayilin spent her whole “plan” (“*barrios bonaerenses*”) in paying the room at the *pensión* (\$150). Therefore, ex-patients have to develop survival strategies for living in the community, such as selling bijouterie (jewelery) or washing cloth for others, as I will describe this in the next chapter. The Hospital also has to support them with as many resources as possible, from the more official food, medicine, and housing (*casas de convivencia*, besides there is no official source of financing designed for the rent and maintenance of these houses), to the more informal and unofficial supply of some furniture, laundry, etc. Professionals of the programs, trying at all costs to discharge patients, also get involved in a series of maneuvers and strategies. For example, the rule is that two persons living together (a couple, even though they are not married) can not receive the national pension, and in order to receive it they should not receive any other income. But Celeste told me that, doing what her doctor had told to her, when she went to sign for the national pension she did not say that she was living with Rodrigo, who has the same pension, plus the new subsidy.

There is no general policy of deinstitutionalization in Argentina; there is no social welfare system contemplating the discharge of inpatients to the community. The social welfare system is the psychiatric hospital, which is free (and mandatory) for them. Nor does the country have a mental health system developed in the community, with a net of mental health centers, day centers, sheltered staffed housing, etc. Despite that, and through all the difficulties generated by a system designed for keeping inside of institutions those labeled as mentally ill, some of them, together with some health workers, have the courage to go out and make the challenge of having a “normal” life. They are few, not a representative number of what is going on in the whole mental health public system, but they are an important beginning. Egidio Clovera Neuropsychiatric Hospital still shows the burden of the backward institution, with custodial nurses and uninterested professionals; the institutional inertia is

strong, but on the other side a new role for the psychiatric hospital shows up from the rehabilitation and discharge programs; if not the closure of the Hospital, its reform begins to seem possible. Next chapter describes in deep one of the externación programs, the Psychosocial Rehabilitation Center, and the lives of patients there getting ready to move out.

## Chapter 3 Moving Out of the Hospital

### **The Psycho-Social Rehabilitation Center**

The Psychosocial Rehabilitation Center (PSRC) was opened in September 2001 in the building of a currently closed ward that once housed patients considered dangerous. The Center formally depends, as the psychiatric chronic wards do, on the Rehabilitation Sub-Direction of the Hospital. But as a matter of fact level the Center depends directly from the Director of the institution. Even though it is located inside the Hospital and in the building of an ex-ward, the Center differs in many aspects from the rest of the wards. As some professionals of Clovera recognized, these wards are custodial instead of rehabilitative, and rehabilitation is made only in a non articulated sense and mostly by employees instead of professionals.

The Psychosocial Rehabilitation Center was opened to work as a real rehabilitative space with a team of psychiatrists, psychologists and social workers preparing long-term chronic patients for being *externados* from Clovera and then following them through the process. “I didn’t want to come to work at the Center, but I’m happy now. It is other thing, another quality of treat; before, we were just custodians,” told me Carolita, the chief nurse of the PSRC. At the Center, patients have psychiatric treatment and psychological therapy. They are encouraged to make choices, take decisions, make projects, and develop domestic and social skills in order to learn or re-learn how to live again in the society. Patients participate in group assemblies composed of patients, professionals and nurses, where they establish the rules for living together. Patients have to clean their rooms, wash their clothes and cook for themselves; they use tablecloths, knives, real glass in the windows, and have their own place and drawers to keep their belongings. “We decide everything in the assemblies; we know that having real glasses in the windows and using real knives may be risky, and in fact we had had some problems, such as a broken window or an incident where someone was threatened with

a knife, but we decide the sanctions in assembly,” says Alicia. Having or doing these things may sound simple or obvious but it makes a big difference from the life in the chronic wards. The center is also mixed, for men and women, and they are around 20 living there (compared to 60 or 70 in many men’s or women’s wards). “The Center was very useful for us. I may have left the hospital without having passed through the Center, but Celeste may not,” told me Rodrigo, and Celeste agreed saying that what they more liked at the Center is that they were very few patients and that they had to cook for themselves.

Originally, Alicia presented the project with Laura, a psychiatrist who started the PSRC with her but is now retired. They developed their ideas together with two psychologists that worked with them in the wards, Julieta, who worked with Laura, and Mariana, who worked with Alicia. Laura retired at the beginning of 2005 and Mariana has recently retired at the end of 2005. In other words, two of the principal and original members of the team have retired, and their full time positions have not been replaced by new professionals<sup>40</sup>.

The Center, according to Alicia, is grassroots’ program that started as a necessity that came up from the floor, not from any policy from the Health Ministry. Some of the ideas for the PSRC appeared before the Dictatorship period of 1976-1983. These ideas try to understand mental illness not from a biologic perspective but from a holist one that takes into account the social and emotional factors that affect a person’s psychic health. It was non organized movement that was swept out completely with the military regime of 1976. Years later, with the return of Democracy and the influences of these previous ideas, Alicia and Laura, both psychiatrists chiefs from two wards, presented a project together for competing for a chief position at the Rehabilitation Service. They understood that the Hospital, which was “a machine for the destruction of a person”, needed a device where a house-like dynamic could be reproduced helping patients to rehabilitate their habits, capabilities, and abilities.

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<sup>40</sup> This is a tendency that can be observed in all the Hospital, where nurses, administrative personnel, and professionals are not being replaced after retirement, in accordance to a plan of budget adjustment. This situation led to continuous claims, strikes, and manifestations as a way of preserving the free public healthcare.

This device had to be created from within Egidio Clovera, answering its real needs. The project was the creation of a Psychosocial Rehabilitation Centre to rehabilitate long-term patients for their *externación* to the community. Even though they won the position, the project had to wait until certain circumstances allowed them to introduce it. This circumstance will appear in relation to problems at the L ward, in 2001.

The L ward was one of the worst backward male wards at Clovera, a high security place enclosing patients with penal cases that were supposed to be very dangerous. Mariana, who knew the place well, says that the ward was always locked and it was “a shelter for the nurses”, since the building of the nurse’s union was located just in front. “With the excuse that it was a dangerous place, the ward was untouchable and nobody could enter. Nurses had total impunity to medicate and punish. Fifty patients lived there as if they were in a wing of a prison. Everything was dirty and patients were completely abandoned.” Finally, the Judicial Power, through *Curaduría*, did an inspection to see how one of their represented patients was, and they made a denunciation that was later followed by other judge’s denounces and the final closure of the ward.

The dangerousness of these patients happened to be a myth, since they were relocated in other wards without problems and even one remained as patient of the new PSRC. When the building was left empty, Alicia and Laura realized that it represented the long awaited circumstances for starting their project; they could use the building for their new program. The Director of the Hospital allowed them to do it and in September of 2001 the Psychosocial Rehabilitation Center opened at the ex L ward building. The bad conditions of the facility allowed only the hosting of three patients, while the building was being repaired. Rodrigo was one of them. “When the Center was opened they called me, but I didn’t want to go because the nurses were saying that since I was being sent to the L ward, it was because something I had done, they made fun of me. But I went. We were only three men, but later came more.”

Only the men's dormitory was opened, but the women who had been evaluated for the program participated in the assemblies while waiting for their dormitory to be ready.

Everyone agreed that peace was over when women arrived. "Women are far more troublesome, they are jealous and gossipy, and they shout and fight more than men. But a good thing was that men started to take care of their appearance," told me Mariana.

The building of the Center is a large square with a very high roof and tall windows that still has the bars used when the building was L ward. There is a large open patio in the middle with a roofed gallery around it, and all the rooms face this patio. The dining/daily room and the kitchen are in one extreme, the doctor and nurse offices are on the opposite extreme (where the front door is), and the dormitories and bathrooms are located at both other sides of the patio. There are some benches on the gallery and very few plants in pots. At the dining-daily room there are wood long tables with benches and a T.V set, and the kitchen is separated by a short wall.

It may be said that the architecture and furniture of the building are not very different from other regular wards. But patients have much more freedom there, as they themselves recognize. The front door is always open and people go in and out all the time; patients have free bus passes and they are allowed to leave the Hospital during the day to go to classes at another institution, to the Pre-Discharge House for some activities, to visit their families or ex-patients (friends, boyfriends or girlfriends), etc. They say that they can take a bath whenever they want, cook, make a tee or *mate* by themselves, stay at their bedrooms during the day, and they can go out. I realized that one of the things that patients most value in the program (together with the possibility of leaving the Hospital) is the possibility of performing actions that we would not consider important a priori because we consider them very simple and always feasible of our choice, but that are impossible to do freely in the regular wards. The freedom of performing these simple actions and the comfortable feeling patients have related to that will increase, of course, when they are *externados* from the Hospital. Davison

and colleagues, even though giving a negative evaluation of the lives of ex-patients in a community in New Haven, recognize that they are more happy than in the hospital because they enjoy “freedoms so mundane and taken for granted by those of us who do not live in institutions that we may never thought to ask about them” (Davison et al 1995:126).

The team in charge of the Psychosocial Rehabilitation Center is presently composed basically by two psychiatrists (Alicia and Gastón) and two psychologists (Julieta and Mariela). A social worker, Mónica, and an occupational therapist used to work there as well as in the Pre-Discharge House, but presently they are not working for the PSRC. The staff from the Center has been requesting the designation of a social worker and an occupational therapist without a satisfactory answer. Originally, psychologists and nurses were in charge of workshops such as medication, management and administration of money, and clothing, while the occupational therapist was in charge of the cooking workshop. But the nurses of the Center are not rehabilitation nurses, and also they and the psychologists do not have time for doing the workshops now. A few social work students from the local University go to do their practical work and a small and changeable number of recently graduated psychologists doing their residence also collaborate with the project (I knew about three in 2005). Most of the members of the team work only part time at the PSRC, being at the same time workers in other dependences of the Hospital. The Center has one nurse at the time, Carolita in the morning (as chief nurse of the ward) and Christian in the afternoon, six hours each. The Center does not have a night staff and during the night they receive any available nurse that the Nurse department sends. As we will see, this situation has caused some problems in the Center.

One of the rules of the Center is that men can not visit the dormitories of the women, and vice versa. The nurses Carolita and Cristian told me about the issue. When the women were close to coming to live at the Center, Carolita brought condoms to explain to the men how to use them. “They can’t have sexual relations here, explained Cristian, but I allow them to go

to an abandoned ward in the back of the hospital. Andrea, for example, tells me that she is going to pick up flowers, and this is our code that means that she and her boyfriend Luis (who is also living at the center) are going to have sexual relations there, and that I should not disturb them”. They have had problems with the guards<sup>41</sup> because they did not want them to go to the back of the institution. But Cristian talked to their chief and solved the problem. He told him that patients “are persons like you and me, and they have their needs as everybody have. Would you like somebody to bother you when you want to be alone with your woman?”

Cristian’s practical and common sense observation about patients as “persons” is one of the Center’s basic statements, opposed to a more biologic paradigm of mental illness that sees patients just as a constellation of symptoms (Dunham and Weinberg 1960), or the behaviors that they display (Johnson 1998). The health professionals at the PSRC agree in that patients’ *externación* from the Hospital should not be made abruptly, taking them from the wards and dumping them in the streets. They complain about that the Hospital and health authorities would like to see a reduction of “beds” (a technocratic and de-personalized term used in reference to in-patients) and reduce costs, but that they do not take into account that patients are persons. The professionals from the Center, instead, are aware of the homeless problem in the United States, and from their experience working in wards they know that patients may have some problems if they leave the Hospital. “The persons who are here are persons; they generate bonds within the hospital and we can not cut these bonds as if they would not exist” said Alicia. Alicia always tries not to use the term “patients” ( a stigmatized label), but its use is very spread in Clovera and even the patients use it, and therefore she also uses the term when she is not careful in avoiding it. She criticizes the biological view of the Hospital Direction, which does not recognize social relationships and feelings. Alicia says that ex-patients will depend on the bonds they constructed at the institution for a while, until

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<sup>41</sup> The hospital has guards with the function of controlling who enters and goes out from the hospital. They watch especially for strangers, but also control what patients do (this control is very lax, since patients go to walk to the nearer streets of the town all the time).

they achieve a total independence from the Hospital. Mariana, in accordance to that, told me that some patients are very well adapted to the Hospital. They are in the highest status of the patients' hierarchy and they act as owners of their ward. They behave and collaborate with the nurses; they do errands for them, and they receive some privileges in exchange such as watching T.V. with the nurses, better food, or some money. This kind of patients, she says, are those who may decompensate when leaving the institution, because they are somebody in the ward, but nobody outside. That is why Mariana says that there is a lot of rehabilitative work to do before and after the *externación*. The PSRC was thought to meet this function.

The aims of the PSRC, as Mariana and Alicia told to me during our conversations, are “to generate a place to stay for those patients in condition of being *externados* but who can't leave the hospital because of social reasons. To generate a dignity and more homogeneous place where we can do rehabilitation”(Marina); “to offer psychosocial rehabilitation in a place where persons can recover their domestic abilities and capabilities, and the autonomy required for the interaction with the environment”(Alicia). The theme of the domestic skills is an important item in the interview for admission at the Center because they emphasizes that patients have to achieve independence, and it is impossible if they do not have self-help (*autovalimiento*). To leave the Center and go to a *casa de convivencia* or *pensión*, patients have to have conscience of their illness, not in terms of diagnosis but of a need of treatment and medication. Patients also have to manage their medication and know their possible symptoms, so in case of being unwell they can anticipate a crisis and warn. Patients also have to make their own projects of life. The Center and also the Pre-Discharge House and the Day Hospital put strong emphasis on the idea of personal projects and future independence.

The ideal for the Professionals of the PSRC is patients achieving a complete autonomy, not depending on the Hospital any more, and a complete integration into the mainstream society. Their expectations may be informed from the concept of *normalization*, even though they do not explicitly refer to it. They expect normalization in its meaning of

wanting ex-patients to be as ‘normal’ as possible and to ‘pass’ unnoticed among other members of society. Johnson describes how staff works in the framework of normalization shape behavior and appearance of mentally disable women in order to make them ‘pass’ within the ‘normal community’(1998:157). I observed the same intents in the professionals from the Center, especially Mariana, who is always concerned with how ex-patients look. The concept of normalization, beyond its good intentions, has been seen as an oppressive pressure over people with psychic problems to achieve “normality” (Johnson 1998:158). It implies that for achieving social integration a person must be as “normal” as possible; Instead of focusing on the need of a change in the way society include people who are different, normalization put the stress of passing as normal on those who are different.

The normalization framework may be oppressive for people seriously disturbed or with serious disabilities, but the ex-patients who participated in my study are those who have, from Clovera Hospital population, the less degree of dependency and passivity, and are more stable and willing of leave the institution. Most of them, I think, can achieve “passing” in the society as regular citizens, especially when they construct a social valued role, without much pressure. The reality is that society in general does not easily accept people who are different, and it may be easier for ex-patients trying to integrate in the society to be just one more neighbor, not *the* (different) neighbor. In fact, ex-patients say that they don’t tell their neighbors about their previous stigmatized identity as patients.

Hearing the PSRC staff talk, I was confused about the differences between self-help (autovalimiento) and autonomy, and Alicia explained it to me: “*autovalimiento*” means being able to perform basic daily activities, such as personal cleaning and dress, and domestic skills that allow them to live without any staff caring of them. This ideal is reinforced by the reality of no community-based staffed housing available. Therefore, patients are required to have self help (*autovalimeinto*) for leaving the Hospital. “*Autonomía*” (Autonomy), on the other and, means a complete integration into the external medium, being able to work, take a bus,

manage money, make proceedings, etc. instead of depending on social workers (or what advocates do in the United States) for that. “I know that not all of us think the same way, but I think that patients have to learn to do everything by themselves. It is better that another patient accompany them than that a social worker do all the proceedings for them,” says Mariana. This autonomy is practiced in the Center, but it is usually achieved during the first months of *externación*. Both, self-help (*autovalimiento*) and autonomy are related to the grade of independence that an ex-patient may have from the hospital. But even a person able of doing all these things may continuous to depend on the hospital economically and materially, since most ex-patients do not have a job or they earn very little money from their jobs or pensions, and they have to rely on the Hospital for food supplies and housing (in the case of the *casas de convivencia*). They may continued to rely on the Hospital emotionally and socially too, after living for decades in the institution with friends, boyfriends, contacts, protégées, and even pets at the hospital. But these dependences are transitory, not permanent. For the PSRC’ professionals, they are supports that will stay until disappear when the person constructs a new life, with social and economical activities, in the outside world. This has happened with some ex-patients, but I think that the bonds that keep in touch other ex-patients with the Hospital world are so strong and so convenient that some ex-patients may never abandon them.

Professionals like to tell about some ex-long term patients who are now living a regular life separated completely from the Hospital. Mariana told me the story of Oscar:

Oscar is a young man who was interned in an institute for minors and then translated to a Sub-Acute ward at the Clovera. Even tough he was institutionalized all his life, he never had a serious treatment. The PSRC evaluated him and called him to live in the Center. He spent five month there and then he moved with Pino and other ex-patients to a *casa de convivencia* in a relatively close town. He did not have any *plan* or subsidy, and he started working picking-up strawberries at a farm in the same town were the Hospital is, where everybody knew him as a patient. But little by little he started to take off. One day, he was listening to a music program at the local radio and phoned the program to ask for a song. He started talking on the phone with the girl who answered, and then they met, started dating, and ended up living together. He helped the woman in her job as independent clothes seller, and then he got a pension

and also a job as custodian in a cyber. He did not say anything to his employer about his past at Egidio Clovera.

Oscar's case shows the PSRC's final goal: the autonomy, a life integrated to the community without depending on the Hospital or another institution. And his case shows the idea of the *casas de convivencia* as transitory places. Oscar's story also influenced other ex-patients, and gives PSRC's patients hope and a proof that it is possible to gain independence and to be accepted within the society.

Of course this achievement is also related to the society's perceptions and attitudes toward the mentally ill. Mariana says that Oscar "doesn't look like a patient, he has a classical dressing style, neat." Most people from the town next to the Hospital mention clothing as the way of identify patients, and that is why the PSRC put attention to this. From the "normalization" discourse, ex-patients should look as other regular citizens. And of course they can do it and they can "pass" unnoticed, as David Romprey -a consumer movement activist from the United States- recognizes: "sure, some of us have the more caricatured features of overmedication that show up in the way we talk or look or dress. But some of us could be beating you in racquetball or dating your sister, and you wouldn't know that we used to be mental patients, to use a kind of pejorative term."<sup>42</sup>

The years lived segregated from society in the Hospital influence the ridiculous and sloppily way of dress of those patients who do not go out too much. Mariana says that they are concerned about that problem in the PSRC. She told me that

"we had workshops and we work a lot about that before; but now we realized that patients learn by themselves when they start going out the hospital. For example, Ester used to dress terrible, she uses a skirt with sport ¾ socks and high heels, and she used a lot of make up in her face, and carried a bag everywhere... But she started going out to visit Mariano [who was living in a *casa de convivencia*] and she saw how people dressed on the streets, and she changed her style by her self."

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<sup>42</sup> *Statesman Journal*, Salem, Oregon. December 21, 2005 "Face of experience pushes state mental-health reform" by Alan Gustafson

However, sometimes doctors and nurses make indications about patients and ex-patients' looks, trying to making them conscious about their appearance; they do it joking, in a paternalistic way, but making patients feel absurd: "I used to tell Pino that he'll get the prize as king of bums" Alicia told me. "He was always with that long old overcoat and his old leather briefcase, and he looked rare. Now you have to see him, he is a sir!" In the same way, I saw Cristian, the nurse, telling a female patient "Lola, look at your hair! It looks like straw! Why don't you brush it a little bit? And that t-shirt? Why are you using it? The woman, around twenty years older than him, smiled ashamed. "It's not nice to tell them such personal things, but we have to because sometimes they don't realize how bad looking they are" says Cristian.

Professionals expect ex-patients to dress "normally," but according to what normality? For lower class people, as all of the ex-patients from Clovera are, the way of dress, sometimes ridiculous or rare, is most related to their poverty than to the years of life inside the institution. Ayilin complains about her monetary impossibility of buying the nice clothes she sees in the stores in the city. All her cloth, sometimes twice her size, sometimes a size smaller than her own, old and out of fashion, are given to her from nurses, teachers, or other people. Some ex-patients are so bad dressed that people confuse them with homeless. I would say that the principal characteristic that explicitly differentiates them from people of a middles class neighborhood or from their health workers is not their illness but the fact that they are poor. I realized, traveling on the bus with one of the ex-patients, that people looked at me surprised, probably because they thought I was talking with a vagabond.

An interesting point is that professionals from the PSRC believe that long-term psychiatric hospital patients with a serious mental illness can recover from their patient role and can live as "normal" people in the community. But not everyone in Clovera believes that; Alicia says that "we had and we still have a strong resistance from infirmary and also from other services. . . "we also have the opposition of other psychiatrist who think that patients are

chronic crazies with nothing to do for them, and that it is a disparate to try to rehabilitate them.”

When I visited the PSRC in August 2003 there was an exciting atmosphere because patients had spent the night alone in the Center, with no nurse in charge. The doctors and psychologists called several times during the night to know how everything was going on. They took that decision as a way of complaining against the institutional inertia and the lack of will from authorities to design competent rehabilitative nurses to the Center. As Alicia put it:

“we don’t have our own night staff and they send us the worst nurses. We don’t want watchmen, we want people who do rehabilitation; but they sent to us the old nurses who used to work here when this was the L ward. When they told me that they did not have other people to send here I told them OK, don’t send anybody.”

The problem of the night nurse staff was explained to me by the Director of the Hospital in an interview in 2003:

“until the year 1965 there was a psychiatric penal unit at the hospital; then it was separated. The psychiatric penal unit went to depend on the Penitentiary System and the hospital separated from the prison. But we had a lot of influence from the prison-like treat. . . you still can see that asymmetric relation between nurses and patients, it still persists in the night, because there are many old people working in the night. . . . I started working at the hospital when I had 20 years and was a medicine student. I was a nurse auxiliary during the night, in the hard nucleus of the hospital. The psychiatric hospital is one during the day and another one during the night, everywhere is like that.”

The revolting decision of leaving the patients alone shows the personal compromise that the team of the PSRC has with the program. They not only offered their nonworking time giving their home telephone numbers in case it was needed but they also compromised their responsibility doing something that others saw as very dangerous and also illegal.

Talking about that with a professional from another sector of the institution, he told me that the issue is that the Center spends all the resources in just a few psychiatric chronic patients, while the Hospital have many needs, not only in the outside psychiatric services but

especially in the general clinic services. “this hospital attends 300.000 patients a year, contrasted to the 1400 patients interned.”

Mariana complains about that

“there is no project from the hospital or from the health Ministry supporting our program.” “There is a new policy of discharging patients but this policy does not consider a pre-discharge work, or a following up when patients go outside. We don’t have a real institutional support.”

With the appearance of the program PREA in 2000 the Provincial Health Ministry sent coaches to Egidio Clovera with the idea of educating in the new world tendencies in mental health and creating a big movement for the *externación* of long-term patients; but this project failed. According to Mariela, the only place where PREA relatively worked was at Clovera Hospital because his own Director created the project, and because of his good relationships with the Health Ministry he got a strong support for the project.

The different wards derive patients to the Center, usually when a patient ask for that but also when they consider that he/she is stable. The Center’s professionals go the wards and evaluate those patients through an interview. They ask them whether they would like to go to live at the Center. “Some of them do not want to leave their ward because they have been there for 30 years; others do not want to come here because they think that it is still the L ward, and other may not want to come because they say ‘I don’t want to work, I come to the hospital to be cure, not to work’ [in reference to the rule that patients have to cook and clean their rooms as part of the rehabilitation of domestic skills]” says Mariana. When Ayilin was still living at the PSRC, she told me: “the others from my ward don’t want to come here because they say that here you have to work. They want all for free at the hospital! But what is wrong with working?”

An important point is that the admission criteria to select patients to go to the PSRC do not take into account their diagnosis. Mariana says that

“the diagnosis is not important for us, but it is important that the patient is stabilized, with certain level of autonomy, with self help (*autovalimiento*) and with desire of going out. Of course we work on that with them here, at the Center, and sometimes our first evaluation is wrong, we make mistakes.”

Alicia agrees saying that

“some patients don’t want to leave and do everything wrong in order to stay. They pee everywhere, refuse to go out, go backwards and we have to send them back to the ward. But in the ward they get better, and they come to the center to visit, and I think that at least something change for good in them after passing through the Center.”

“Our ward [the PSRC], which is a pilot ward, does not have very many patients yet. Other patients wanted to come here but they couldn’t come; as soon as all of us leave they will start coming in.” told me Rodrigo in 2003. This scarcity of room for new patients continuing to be a problem, as Micaela, a psychiatrist from a chronic ward, told me.

“I have 10 patients who are ready to be externados right now; they are supposed to go through the PSRC before going to a casa de convivencia, but the Center has room for only 20 patients and there are no places now. Besides, the *Externación* Service (Pre-Discharge) has a criterion that I don’t share: they don’t accept patients with personality disorder. Why?”

Micaela is critical about the programs (the Pre-Discharge, Day Hospital and Psychosocial Rehabilitation Center) and does not participate in them. She has been in Trieste leaning about the Italian mental health system reform, and feels frustrated about the lack of political decision in making a change in Argentina and about not having a national or provincial legislation that contemplates a plan of hospitals’ closure<sup>43</sup>. Alicia, Mariana, Patricia, Nora and other professionals running the programs do not agree to start by closing the Hospital; they think that the programs are resisting and transforming the system from within, breaking it little by little. Micaela, instead, thinks that it is not possible to make a change in the system without a general policy and when “each one is working for himself”

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<sup>43</sup> In Italy, the psychiatrist Franco Besaglia and his antipsychiatric movement “democratic psychiatry” made deinstitutionalization a political issue debated widely in Italian society, ending with the promulgation of Law 180 (1978) that prohibited the internment of the mentally ill in psychiatric hospitals. Another law, in 1994, enforced the final closure of all the asylums.

and when the programs are devoted to so few patients. She asked for table cloth, knives and forks, in order to rehabilitate her patients in her ward (since there is no room in the PSRC) and the answer was negative because the PSRC is the place for doing that. For her, the PSRC and the other programs are “functional to the present asylum system”. They appear on the web page of the institution and in the news showing reforms and changes that in fact only affect a small number of patients, professionals, and budget.

Micaela as well as Patricia, Nora, or Alicia agree in that the Argentinean public mental health system has to be improved with an integral health system where mental health services are not separated from other services in the community, and where especial attention is paid to the following up of ex-patients in the community. But they disagree about the ways of doing that, and in the place of the psychiatric hospital in the process. Micaela, as other few health workers, expects the prohibition of internments and a legislation and general policy of *desmanicomialización*. Alicia, the member of the PSRC team who most express her ideas and critical views, usually in a political combative way, thinks differently. She says that “I work from the base [below, the grass], I think that the revolution is made step by step, as needs arise.” We can see the same ideological differences pushing and slowing the process of *desmanicomialización* outside the Hospital, in the academia and the political sphere. The *manicomio*, the public psychiatric hospital, is at the same time criticized for its dehumanized conditions and acclaimed for its humanitarian function as the only shelter for the poor and mentally ill. The State responsibility for these people has been, since late nineteenth century, filled through the asylums, and presently many people is afraid that the destruction of such public institution may carry the vanishing of the State responsibility and a process of privatization of the public health system. As we will see in next chapter, this privatization of mental health services has happened in the United States, where deinstitutionalization is opening the door to a profitable business.

## **Planning for Moving Out of the Hospital**

I have known María, Ester, Mariano, Pino, Ayilin, Celeste, and Rodrigo since they were living at the Psychosocial Rehabilitation Center. I had the opportunity to know some of the fears, doubts, projects, hopes, efforts, and achievements that they had during the process of leaving their wards, moving to the PSRC, and finally going to live in the outside world. All of them have been interned for at least 20 years, but they were not the passive chronic “inmate” totally institutionalized in the role of patient. As we saw in chapter one, they reduce their institutionalism by working, making social relationships, and finding social roles within the Hospital.

They entered the PSRC with suspect and doubts, fearing about leaving the known and manageable place at their wards for entering what were to be a novel experience. But the finality of the PSRC was clear and attractive: “the Psychosocial Rehabilitation Center is a new pilot test which consists in rehabilitate patients and give them the discharge with a subsidy and a casita de convivencia,” told me Rodrigo in 2003. Ayilin was unsure about leaving a chronic ward where she knew she was “wasting her life among old women” but where she had a recognized role taking care of the old ladies. “They came to take me from the Z ward, and I didn’t want to go. I told them: I am very happy here with the ‘*viejitas*’ (little old ladies), I will die in this ward. But they said I was recovered, and that I could not stay with old women; and I went to the psychosocial (Rehabilitation Center) by myself, with my bag.”

These men and women stayed two or three years at the PSRC, where they got prepared for living outside not only by rehabilitating their forgotten abilities and growing their self esteem and confidence, but also re-contacting family members, getting some jobs and activities at Clovera, saving money, and planning their personal future with the support of the staff and with mutual accompaniment. In different degrees of compromise and solidarity, they support each other listening about projects and possibilities, suggesting actions, telling about opportunities for a job, a bus pass, a social plan, a cheap house or furniture, etc.

Everyone at the PSRC knew about others' activities and plans, and they accompanied each other in their achievements and problems. This bond created inside the Hospital, a bond of “*compañeros*” (partners) sharing the same experience and confronting the same fears and problems, would continue for most of them outside the Hospital.

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Money is a serious issue in relation to any plan for *externación* and discharge, and professionals at the PSRC and P-DH chase all the few available resources. When Ayilin, Celeste, and all of them were living at the PSRC they received a *peculio*<sup>44</sup>, and Celeste, Ester, Rodrigo, Mariano, and Ayilin had a “plan”<sup>45</sup>. Rodrigo had the “*barrios bonaerenses*” plan, in exchange for his work picking-up cardboard inside the institution; Celeste had a plan “*jefas y jefes de hogar*” working as a waitress in the general pavilion, and Ester had the same plan cleaning a women bathroom at the general pavilion, where she also got tips. According to the professionals from the PSRC, they have try to arrange with hospital staff for other kinds of jobs for the patients to do in exchange for the plans, but “the personnel of this hospital is who most discriminate them.” María did not receive any plan because she did not have her DNI (national identity document) and social workers worked in the proceedings for it with no success. “You would be surprise to know how many patients at the hospital don’t have their DNI,” told me Mónica, a social worker from the P-DH who has work at the PSRC before. In her opinion, without a DNI it is impossible to obtain independence. Anyway, María was one of the first from the PSRC in going to a *casa de convivencia*, and she still does not have a DNI. When she was living at the Center she sold products from the hospital workshops inside the institution.

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<sup>44</sup> Traditionally the health Ministry pays around \$30 pesos to each of those patients who help doing the cleaning or other duties in the hospital ( a few patients at each ward). The PSRC registered all its patients for the *peculio*, because all of them do domestic work at the center. Usually, nurses or sometimes doctors keep this money and give it to the patients little by little. This payment have been suspended for long periods of time, and in 2005 (when all the ex-patients were leaving outside the hospital and therefore not receiving a *peculio* any more) government decided to pay some overdue payments, and they received a considerable amount of overdue money.

<sup>45</sup> Plan “*barrios bonaerenses*” and “*jefas y jefes de hogar*”, described in the previous chapter

Patients at the PSRC started to know how life outside Clovera could be, and they sent out for visits and activities, starting to need new things such as more money, which they spend in their needs and they saved or brought the things they were going to need when leaving the Hospital. They and their health professionals worked together in applications for the national pension for disability and other possible benefits.

They also worked for making contacts with family members. Rodrigo and Celeste still are thrilled remembering the day his daughter called him at the PSRC. Neither his ex-wife nor his son and daughter knew that he had been interned at Clovera all these years. A social worker helped him find them and their address in the electoral lists, and Rodrigo sent letters to them. One of the letters returned because his son was not living there any more, but the other letter was received from her daughter and she called him at the Hospital. She also put Rodrigo in contact with his son, and he says that “It was a fest, a big emotion, everyone in the center cried when I phoned and my children accepted me.” His son and daughter then decided to visit him, and they slept at the PSRC for a night. His son remembered him, but his daughter didn’t. Later, the Center staff arranged with the Cooperative Association to give Rodrigo a loan for buying the tickets for the trip, and he went with Celeste to spend Christmas with his and know his grandsons. He re-established a relationship with them and incorporated Celeste as a grandmother for the children.

Patients with boyfriend/girlfriend went to visit their relatives with them, incorporating them as their couples and introducing them to their relatives. Celeste and Rodrigo also went to visit Celeste’s sister; Mariano and Ester went to visit Ester’s father, and María went with her boyfriend Sebastián to visit her sister. Living at the PSRC, some of them also reinforced ties: Rodrigo and Celeste got engaged at the center and they started functioning as a couple: they shared their savings, participated in common strategies for obtaining products of their needs,

such as a “*Club del Trueque*” (exchange club<sup>46</sup>), they traveled together to visit relatives, they had a dog as a pet, and they brought a refrigerator and other things for the day they would leave the Hospital. They decided that they only will leave the Hospital together. The decision delayed their departure from the institution because no housing arrangements for couples existed. “They said that they will give us a little house for both to *convivir* (live together, share the same life); but now the Doctor says that it is difficult for couples because the Ministry does not pay for that<sup>47</sup>.” Both Celeste and especially Rodrigo had several offers to go to female and male *casas de convivencia*, but they refused the offers. “La negra is my ball and chain, I’m stuck with her, I couldn’t think of live without her,” said Rodrigo. They had always projects: Rodrigo and Celeste were going to live in a house that Solo, the director of the hospital Theater, offered to them and where they had to pay only expenses; later the Director of the Hospital personally would rent a house as a *casa de convivencia* for couples, and then they were in a waiting list for a housing program from the province government. Rodrigo sent me a letter in July 2004, from the PSRC, in which he says that “things are getting along well around here, we are still waiting for the house (it’s only a matter of patience).” And they sent me a sticker saying “I don’t have everything I love, but I love everything I have”. Finally, after that none of these projects worked, they moved out by themselves, renting a small cheap house at the backyard of another house. They had heard a nurse assistant talking about a neighbor who wanted to rent a cabin (*casilla*), and they got interested and went to see the place and rented it for \$100 a month. “We are the pioneers, the first couple leaving the hospital together”, they say proudly.

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<sup>46</sup> The *Club del Trueque* (non monetary exchange of services and products) functioned during 2002 and 2003 inside the Hospital. It was coordinated by an administrative employee, and its participants were patients, low employees, and neighbors from outside. They participated exchanging products. This *club del Trueque* belonged to a “solidarity network” of exchange clubs developed by the Argentineans during the worst years of economical crisis, as a way of coping with basic needs without using money. (See Leoni and Luzzi 2003).

<sup>47</sup> In fact the ministry does not finance any *casa de convivencia*, which are paid by the Hospital. The decision of not allowing couple to live there comes from the Pre Discharge program professionals in charge of the houses.

Mariano decided to go to a male *casa de convivencia* but only with the promise of renting a house with Ester as soon as it was possible. She told me about that in 2003:

“I have my boyfriend Mariano Rojas, I know him from a ward. All my family knows that I will leave the hospital with him. . . . I’m saving money because Mariano Rojas will go to a *casa de convivencia* but then he will come to take me when I receive a pension from my father. . . and we will rent a house, or maybe a *pensión* in the city.”

He had lost the “plan” and she was waiting for a pension, and only after more than two years, in February of 2006, they finally moved together to a house that they rented to a nurse from Clovera for around \$200 pesos a month.

In general ex-patients remember their life at the Center as much better than their lives at the wards, with more freedom for cooking, going out, having a bath whenever they wanted, or making projects such as the library that Rodrigo organized. But some of them are also critics of some things. Mariano, for example, criticizes arbitrary and authoritarian actions or decisions at the center, even recognizing that they have many opportunities to decide than in the ward. He says that the Center could discharge more patients and more quickly, since some patients at the Center may be getting more money than him who is outside. He also says that “*The center is not like they say* (a place previous to the discharge). Even though if you are lucid, if you fight with someone they take you out, they send you back to a ward.” According to other ex-patients, this is what happened with Sebastián, María’s boyfriend, when he fought with Mariano. When she was at the PSRC Ayilin told me that “I like here because I can do my meals, I can cook, I help in the dinner room...If there are oranges, I make juice and nobody tells me anything. Or if there is oil, I re-heat some *milanesitas* (meat) that I share with the others.” But now that she is living out from the Hospital she says that what she disliked from the Center is that she had to live with male patients, and everyone there was...(she makes gestures as saying “crazy”).

An important aspect of the professionals from the Center is that they respect patients’ desires when planning their discharge. Rodrigo and Celeste wanted to leave Egidio Clovera

only together and their desire was respected; none of them was forced to go to a *casa de convivencia*. Ayilin received an offer to go out to live with María and Mercedes in their *casa de convivencia* but she didn't want to go. She says that being a very hygienic person she wanted to have her own bathroom. "She does not get along with anybody", other patients told me. But her desires were respected and after two years at the Rehabilitation Center, at the beginning of 2005, her psychiatrist Laura told her: "Ayilin, before my retirement I will give you a surprise" and Ayilin went to live at the *pensión*, alone as she wanted. "Anita Selva accompanied me to the *pensión*. We took the bus. Anita and Carolita gave me two quilts. Later, Juan brought me my furniture (a closet and a night table)" (Anita is the nurses' supervisor, Carolita is the chief nurse from the PSRC, and Juan is a nurse at the Pre-discharge house). Daniel also remembers: "they gave me two options, a *casa de convivencia* or a *pensión*, and since I think that a *pensión* is a depressing place, I choose a *casa de convivencia*."

None of the ex-patients went to live to their previous neighborhood after their *externación*. Clovera Hospital receives patients from the whole province and sometimes from other provinces too, and after many years of internment and loose of contact with their previous reality, family and friends, people may not have much interest in going back to their towns, beyond that after twenty years their families may have move to new places. Besides, they constructed social bonds close to the Hospital, they have something there and nothing in their previous towns. The following-up for their *externación* is done from the Hospital, and there is no network system of mental health care developed in the communities<sup>48</sup>. Some of the ex-patients arrived to the Hospital from other institutions and not from their original neighborhoods. For these and probably many other reasons, ex-patients did not really "go

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<sup>48</sup> The Hospital has a program, "*altas en red*" which is supposed to establish contact between the Hospital and a medical center in the province and town where ex-patients return. It is managed by the Social Service of the Hospital, but as I could notice it is not developed and it is not well known by other professionals of the Hospital. Those who know about it, say that it is a program "just for sending medication."

back to the community” in the sense of returning to their communities after hospitalization. They remain living relatively close to the institution, in different neighborhoods but in the same parish. Looking at this fact from its positive side, the new neighbors do not know about their past, and if their past previous to hospitalization is a stigmatized one (it could be a past of homelessness, crisis, some violence, arrests, etc), it is a good thing.

I do not know what ex-patients will do in the future, but none of them suggested the idea of moving far from their present parish. They want to visit their previous towns (Celeste wants to go to her natal province, for example) but not to move there. For now, they still depend on the Hospital for their living, their treatment, and a large part of their social life. They go to the PSRC for treatment; some of them have been derived to psychologist and psychiatrists at the Pre-Discharge house or at the external clinics from the Acute sector of the Hospital, but they still go to the Psychosocial Rehabilitation Center for picking up their food supplies or for visiting.

The following is a description from my field notes of the day of the week when all of the ex-patients go to the PSRC to pick up their food supplies, medicines, weekly discharge certificate, and to be seen by their psychiatrist and psychologist. They also use the day as a social event to see each other and exchange information, and to see long-time known employees and the “*compañeros*” who are still interned at the institution.

Thursday , June 10<sup>th</sup> 2005. 10:00 AM

I met Pino in front of the PSRC; he had just taken the food provisions for the week. He was greeting other ex-patients who were entering the Center with their domestic shopping bags. Pino showed me his bags full of small plastic bags containing eggs, flour, polenta (thick corn flour), flan mix, rice, condiments, and different kinds of vegetables. “On Monday we have to come back for the meat, they will give us four kilograms,” he told me. We talk for a while at the door of the Center, and Pino was giving me María’s address when she appeared with Andrea (still living at the Center). María had a bag with baby cloth, and Andrea had wool hats. They were selling it. “A friend of mine makes them and I give these to Andrea so she can sell too,” María explained to me. They left in direction to the general pavilion to sell their stuff there. I entered the Center and Pino accompanied me. We met Rodrigo and Pedro in the patio. “I already got the meat for the potatoes pie! I asked for it the other day and they gave it to me today” told me Rodrigo, who had invited me for lunch the following day. Pedro had been visiting her girlfriend Iris at the K ward earlier in the morning. “She is coming to

live at the Center soon,” he told me. We started talking about jobs and Pedro said that he was trying to find a job but it was difficult because of the discrimination. “People know that you are from Clovera Hospital and they discriminate against you.” Ester came out from the dormitories to tell me that she and Mariano (her boyfriend living in a *casa de convivencia*) has seen a house and rented it. Rodrigo, Pedro and Pino made a circle with Ester to talk about that. I greeted them and entered the doctor’s office to say hello to Alicia and Julieta. After a minute someone knocked at the door and entered without waiting; it was Celeste accompanied by Rodrigo. She was ready to receive her definitive discharge certificate after five months of living with Rodrigo. When signing the discharge certificates, Alicia said: *cha cha cha chan!* trying to give the moment some importance, but the act had no real magnitude. It seemed to me that the real important moment had had been before, when Celeste and Rodrigo moved to the house. The discharge certificate did not have, for Celeste, the signification that I was expecting, about being finally free from the institution. Celeste did OK to me with her thumb with a smile of complicity. She looked happy, but she also was a little worried. “Do I still have to come to receive the medication here?,” she asked. “Well, for now we still have medication for you, but you are not a patient from the Center any more, and you will have to get your medicines at the hospital pharmacy” answered Alicia. Celeste, a bit anguished, asked if she can continue going for “control” to the center. “It is not ‘control’! Who I am, a police? It is following up, it is treatment, not control!,” shouted Alicia, and Celeste seemed confused. “Don’t worry, Celeste, I will control you all your life!! If for you what we do is ‘control’ it is OK, we will control you,” told her Julieta in a kind voice, and everybody laughed. When we left the doctors’ office I went with Rodrigo to the post from the Hospital farm where he was working as a seller. He showed me the vegetables that they sold, and I brought him some spinach and honey. He greeted and was greeted by all the patients and hospital employees who passed in front of the post, and they made jokes, for example about soccer teams. Ayilin saw me and run to say hello. She was coming from the Hospital bank where she has her little money. “She has a lot of money in the bank, and she is saving since she was living at the Center and receiving a plan”, explain to me Rodrigo. When I left the Hospital I could see María and Sofía sitting at the front door of the Center with their domestic-shopping bags full of supplies, and talking with other patients of the Center. From the bus stop I could see Pino and Pedro coming, and the people at the street stands greeted them saying their names. At the bus stop, Pedro came to talk with me and Pino talked with a hospital’ administrative secretary that he has known for a long time. We waited for the bus for about 50 minutes.

This passage shows the importance of the Hospital as a social space where ex-patients find material (food), medical (treatment, medicines), and social (professionals, employees, other ex-patients) support. Ex-patients interact in this space socializing concerns and accounts of their outside experiences of life, and they find there support and affection. This social world belongs to the “psychiatric sphere,” but it is valued instead of stigmatized. As we will see in the next chapters, psychiatric and outside worlds are not separated but rather integrated by ex-patients.

## Chapter 4 A New Life Outside the Hospital

### **Life in a *Casa de Convivencia***

I will describe here the life in two *casas de convivencia*, one for women and one for men, as I knew it during my fieldwork in 2005.

#### **María, Sofía, and “la Abuela”**

After 36 years at the X ward and two years and two months at the Psychosocial Rehabilitation Center, María went to live in a *casa de convivencia* with Mercedes and Sofía in 2003. María invited me to visit her at the house, so she could introduce me to her *compañeras* (partners). She insisted in that I should go only on Wednesday or Sunday because she and Sofía were always out working, and Mercedes did not open the door to strangers (verify after three times of going to their house and hearing Mercedes shouting, without opening the door, that María was not at home and that I should come back another day). Finally, I found them on a Wednesday morning. The staff from the Pre-Discharge House, who is in charged of the supervision of the *casas de convivencia*, was visiting them.

The house is located in an urban neighborhood just in the limits of the city. It is less than two miles from the commercial and civic center of the city and 3, 5 miles from the Hospital, and the bus stop to go to both places is just half block from the house. It is a middle class zone with long-time ago established houses and many small stores such as *kioscos*<sup>49</sup> (drug store) a bazaar, a butchery, a book store, or a bakery. The women say that the neighbors are very gentle, but given that they do not want to bother their neighbors, they do not talk with them too much. They only interact with owners or employees at stores. The house is at the end of a long corridor with other apartments facing it. The corridor has a door to the sidewalk with an electrical porter.

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<sup>49</sup> There are many *Kioscos* (which sell candy, cookies, and cigarettes) in urban and also suburban neighborhoods, as well as in the center of the main city.

The house has white painted walls and tiled floor, it has two bedrooms, one small for Mercedes and another bigger for María and Sofía; a dining room separated from the kitchen by a short wall, one bathroom, and a small patio. The kitchen is very narrow and has a small gas stove and a sink and kitchen chest; the dining room has just a table with chairs around, a cabinet, a small green plant in a pot on the floor, and a refrigerator. The bedrooms have a clothier and the beds, and María has a night table that a nun from Clovera gave to her. All the dishes and furniture, with the exception of the night table and some dishes from Sofía, belong to the Hospital. Everything looks in order and very clean, but it seems that the women were recently moved to the place (rather than one year ago); there is no decoration or personal objects so common in homes. The place seems cold, with a lack of personality and commodities. Only Mercedes' bedroom has lots of bags, bottles, and different objects on the floor, giving to the place some peculiarity. I would say that the ambient resemble in some way the austerity of the Hospital; even Mercedes' room with her accumulation of things resembles some wards where patients accumulate bags and boxes under their beds, their only personal territories.

The lack of personality and personal appropriateness of the house may be explained by different reasons, and lack of resources for ornaments and furniture is one of them. But we also have to consider that the house is transitory and depending from the Hospital, and the women are supposed to live there as in a regular house in a neighborhood but it is not their permanent home. There is a big difference with other descriptions of community-based permanent housing for former patients, according to the experiences in other countries. Mc Court Perring (1993), for example, describes a group home (in England) as very different from a hospital ward:

All the rooms except kitchen, bathroom and toilets are carpeted, and are painted in cool colors, such as pale blue . . . the living room has four armchairs, with coffee tables between them, a small bookcase with a few books, sideboard, and a large color TV. The walls are now hung with photographs and the paintings of one resident, and all available surfaces are decorated with plants, flowers, pottery bought in the

hospital occupational therapy department sales, and more paintings. Birthday cards from relatives and postcards from staff are displayed for long periods. Coffee cups and magazines lie here and there on the tables. The kitchen has fitted units, dinning table and folding chairs, a large fridge/freezer, electric cooker, and automatic washing machine. . . the bedrooms had a divan, fitted wardrobe and chest of drawers for each resident. . . (Mc Court Perring 1993: 131)

The houses rented by Clovera Hospital, instead, retain some of the institutional characteristics in their austerity and coldness. I think that the fact that the women did not transform it adding more personal ornaments or things is a sign both of their lack of personal items from their previous life (especially photographs), their lack of resources and their understanding of the place as not really own but a hospital one. However, the women say that they are well at the house and they are happy to live there instead of in the Hospital.

María and Sofía, who are younger than Mercedes, have several occupations during the week (María is 57 and Sofía is around the same age, while Mercedes is 72). These occupations are not organized from the mental health system (what is equal to the psychiatric hospital) as planned activities for discharged patients. None of them participate of the workshops at the Day Hospital (inside Clovera Hospital) nor of the workshops at the Pre-Discharge House in the city. Sofía works as domestic employee in a store, and María have different jobs that, even tough they are related in some way to the institution, are no planned for her but she found them asking, walking, talking to known people. María told me about her activities: she works at the Cooperative Association of the Hospital once a week, doing the cleaning; Alicia (her doctor from the PSRC) found this job for her; “I know that working at the hospital is not the best solution, but at least is something until they find another job”, she told me. María also works three days a week cleaning the house of a Hospital’s hairdresser, a woman who has known María for many years and from whom she says that “more than my *patrona* (boss, master) she is my friend; I know her since 25 years ago”. The sister in law of this woman gives María baby cloth to sell, and this is another way in which María earns some money. The last time I saw her in December 2006 she was not selling cloth any more but

selling AVON products. These jobs are done in an informal way because María does not have documents for doing it formally, but she manages to find some income anyway.

Very occasionally María sees her sister, but her social relationships are tied to the Hospital world. She has her “friends” there, such as the hairdresser, the sewer workshop teacher or a nun, and she has her boyfriend Sebastián there, too. When I saw them in December 2005 María and Sofía told me that Sebastián went to spend Christmas with them at their house. “He made chicken and meat in the oven for all of us” said Sofía very excited because she is who usually cooks. For the New Year Celebration Sofía had made arrangements to go to her *patrona*’ s house (her boss’ house), and María arranged to spend the night of the 31<sup>st</sup> at the Psychosocial Rehabilitation Center (PSRC), with the patients that she has known for years. She still goes to the PSRC for her medication and therapy once a week, and to visit the patients there.

Mercedes or “the granny” (*la abuela*), as María and Sofía call her, has a small clothier in her bedroom locked with a padlock (a practice common in the institution for those few patients who have a furniture), and tons of plastic bags, bottles, and boxes accumulated in the floor of the room. When I entered her bedroom she quickly said that “everything is necessary” before I could ask anything. Probably she is used to the health workers critics about her habit. She had bags with cloth, bottles with shampoo, a washbasin, a jar, and many things that do not fit in the small clothier. She had put her mattress to ventilate standing up over the bed frame, another custom from the institution. Saw her going to the kitchen and preparing broth with an egg without salt (she cannot eat with salt) while singing soft, and then going to eat it in her bedroom, sitting at the frame of her bed. I asked why she ate there instead of eating at the table, “because I’m warmer in here” she said.

Mercedes complains because her sons do not visit her, and she does not have contact with other relatives. She told me that she goes every Sunday to a church that is two blocks far from the apartment, and she also go frequently to Egidio Clovera to see “her child,” a young

patient from her old ward with whom Mercedes made a strong bond. She goes frequently to the Hospital to take care of her and give her cloth. When I saw María and Sofía at the Hospital during my last week of fieldwork I asked for Dolores. “She is still recovering from the bites of five dogs, but she is fine now” they said. When Dolores went to visit “her child” at a Hospital ward located in the back of the institution she was attacked by dogs<sup>50</sup>. Beyond these activities, Mercedes stays at home most of the time. This is not an uncommon thing at her age (72), when people are usually retired, and it should not be seen as a symptom of her mental illness. Mc Court Perring (1993) analyses the popular ideas about the mental illness of former patients living in the community in England. She says that the mentally ill person is commonly seen as non social and easy to become “depressed” (in the everyday language and common sense meaning), and this ideas let voluntaries in charged of group homes to require residents to fully participate in all the domestic activities and to go to scheduled everyday activities outside the house, even when some of the people were seventy or eighty years old.

The three women at the *casa de convivencia* divide the domestic activities according to the abilities, time available, and preferences of each one. Mercedes, who stays more time than the others at the apartment, cleans the house most of the times, and she also makes the laundry. Sofía likes to cook and does it very well. She cooks every day for herself and for María, and sometimes for María’s boyfriend. Mercedes prepares a special food for her, consisting mostly in soups. Sofía says that María does not do too much but spends the time with her boyfriend. Sofía also says that she has to put her own money to buy things and food for the house because María does not have enough. Being at the house I could see Sofía giving María \$10 pesos to buy meat. María’s boyfriend was coming for lunch. They receive

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<sup>50</sup> The dog’s problem in the hospital is not new, but it was raised by the hospital employees union in 2005 as an important item for the growth in their salaries because of the increase in the job’s dangerously. Several attacks to patients and personnel appeared in the local newspapers that showed the dogs at the hospital as a “growing threat”. The hospital have always have dogs because patients in the wards take them as their pets, regardless doctors’ disagreement. But the wild dogs that exist in the fields behind the hospital enter the hospital attacking people especially during the night or early in the morning. Time by time the hospital contacts a dog-control institute from a relatively close city to eliminate the dogs.

the food supplies from the Hospital as well as the other ex-patients, but they do not receive meat and other expensive supplies very often, and Sofía put her money for the food of the others.

I was present during a visit of the “*asistentes*” (social workers) of the P-DH staff for supervision. They were three female social workers and a male nurse, and they were sitting at the table with Mercedes while Sofía was serving *mate* to them. The staff was wearing regular everyday cloth, not a hospital dustcover, and the environment seemed relaxed. Mónica, one of the social workers, told me that their policy is not to tell the neighbors that the women are ex- hospital patients, allowing them to establish the relationship that they want with the neighbors. If they do not want to tell them about their past at the Hospital it is all right. They come to the visits “disguised”, wearing regular cloth as if they were just friends. Even though the environment seemed friendly, and there were pastries in a plate at the table, neither Sofía nor María or Mercedes were drinking *mate*, and Sofía did not offer *mate* to me either. The hospital typical distance between patients and professionals and nurses was reproduced, in a minor degree, in this act, because patients do not drink *mate* with professionals at the Hospital. Because María introduced me to Sofía as “the girl from the exchange club” (*club del trueque*<sup>51</sup>), probably Sofía considered me not a health professional, and she only offered *mate* to me when the health workers left, and she and María drank with me. “I drink *mate* with you now, but I don’t drink with the ‘assistants’ or the doctors, I offer *mate* to them but I don’t drink with them for respect, because maybe they are picky,” Sofía told me.

The staff talked with the women about house matters, such as whether the plumber had fixed a leak that causes a humidity problem or if the heater had been installed. After asking about the house, they talked with the woman about their own issues, such as how was Mercedes’ arm; María’s lack of ID (social workers have been trying for years to make her a

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<sup>51</sup> The *Club del Trueque* (non monetary exchange of services and products) explained in a footnote in chapter 3. I met María there.

DNI but the problem is that probably she was not registered when she was born, and nobody knows exactly where it was); or María's boyfriend possibilities of *externación*. Sofía told to the social workers that María spent a lot of time at the Hospital visiting her boyfriend (something that professionals do not like too much because of the independence and normalization ideal). Sebastián was living with María at the PSRC, but because of a fight with Ester's boyfriend (Mariano) he was sent back to a hospital ward, losing the opportunity to leave the Hospital. "He was going to come out, but because of that problem he couldn't. Now he only has permission to come to visit me here and to visit his family," explained María.

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The extremely long-term institutionalization period and the advanced age of the three women, beyond their diagnosis, are factors difficult to jump over, and the ideal of a short transitional time in the house until they find an alternative independent option has been made more flexible for them. The Hospital is for them a multiple resource for their material and social life, a paternalistic hand of the remaining welfare State and a well known world of social relationships where they find job opportunities, friends, love, and also a social role (in the case of Mercedes with "her child"). But the three women also started to build a new social world outside the institution, managing their reinsertion in society with caution, not "bothering" but doing ordinary things that ordinary people do, such as shopping at the neighborhood stores, going to the neighborhood church, asking the neighbors for some help (they made arrangements with a woman neighbor for borrowing a hose to have water in the house when they did not have), and doing all the domestic tasks in the house. And as Sofía says, they are "very well, very well. It has been more than one year that we are here and we are very well," says Sofía. The ideals of independence from the Hospital and complete autonomy that the professionals of the programs have are far from being achieved, especially for María, with a boyfriend still in a Hospital ward and with no ID, and for Mercedes, because

of her age. But the achievements these three women have done are enough for showing the importance of these programs at the Hospital.

### **Pino, Mariano, Jorge, and Daniel**

The *casa de convivencia* where Pino, Jorge, Daniel, and (until very recently) Mariano live is an apartment in a three-story building located in the commercial center of a town next to the city and five miles from Clovera Hospital. This commercial center is surrounded by lower middle class and low income neighborhoods, and is not as expensive as the commercial center of the main city. There are always many people in the streets.

Pedro, who I met at the institution through Pino, invited me to visit them but he suggested me to go after 6:00PM, when everyone comes back to the house. Being with Pino at the Pre-Discharge House we arranged to go together to the house after work. I picked him up at 5:30 and we took the bus to his apartment. There, we set at the table to drink *mate* with Mariano and Jorge, and they introduced me to Daniel when he arrived and joined us at the table. The apartment is on the second floor and it is accessible directly from the street. It has two big bedrooms and another one smaller, one bathroom, a kitchen, a small patio-terrace and a dinning room. In general, the apartment looks as the women's *casa de convivencia*, austere and cold. The men have no other commodities beyond telephone and TV in the dinning room, but there is no furniture besides a gas heater and the table and chairs. The place is impregnate of the smell of cigarette, and there is a lot of smoke. Everything looks in order and relatively clean.

The four men are in their late forties or fifty years old. All of them have been living at the Psychosocial Rehabilitation Center after being interned in hospital wards. Pino and Mariano were interned for 20 and 21 years, but Pedro and Daniel had shorted internments, of four years Pedro and one year after three previous interments Daniel. Pino arrived at the house in October 2003 with other *compañeros* (partners) and was shortly followed by Mariano. Pedro went there in June 2004, and Daniel just one month and a half before I went

there; he went to live there in June 2005. They were waiting the arrival of another *compañero* from the PSRC, because the house has space for five men. All of them are involved in daily activities such as workshops, search for a job, jobs, and visits to friends/girlfriends. Pedro and Mariano have their girlfriends at the Hospital, and Pino's girlfriend lives in the main city. They return to the apartment just after it is getting dark, around 6:00 in winter.

They recognize that it is no easy to live together four men at the same house. Pedro says that they have to learn to live one with the other. "One thing is to live in the ward, having the nurses' and doctors' contention. Here is different, we have to learn to tolerate one to each other, and at the beginning it is hard. It's no easy to learn to tolerate each one's personalities, and one not everyday awake the same. Mariano insists in that people have to put willpower in order to live at a *casa de convivencia*, "some ones don't want to stay, they don't get used to," and he talks about other two persons who started to "*andar mal*" (be unwell), stopped taking their medication, and went back to the Hospital. "They didn't want to be here, they didn't have willpower." Mariano says that there is no limit of time for being at the house. "You put your own limit if you do things well."

Pre-Discharge sends therapists and nurses once a month to see how everything is going on, but most ex-patients have liberty to decide what to do, how to organize the domestic issues. "Each one put what he can, and we share. The common pool doesn't work", explained to me Mariano. "For example, the TV belongs to Mariano, but he left the TV here at the dinning room for all of us to use it", said Pino. Mariano cooks most of the times, because he works at a bakery workshop and he knows how to prepare good foods. But they share the cooking work too, with the exception of Pino "who never does anything" say the others laughing. "At noon maybe not, but for dinner we eat all together" says Daniel. They do not spend too much time at the house, and they commonly arrived home when it is getting dark. They say that they organize work at the house in the moment. They are accustomed to organize in group for that because at the PSRC they distributed tasks for everything. The

institution provides them with the food supplies, but they have to buy the products for cleaning.

Pino works in the mornings as a seller of plastic bags (trash bags, pathologic bags, etc) made at a Hospital workshop. He has been doing this job for many years, even before going to live at the PSRC when he had a permit for selling outside Clovera. He gets a 10% of the sales as a salary. In the afternoons, Pino is always involved in activities outside the house. When I was doing fieldwork he had stated to work at the Pre-Discharge House selling the products of the P-DH workshops. He goes there three times a week from 1:30 to 5:00 PM., and he gets also a percentage (10 or 20%) of the sales, which were around \$30 pesos a day. It was not too much money, but helps, and he does not pay transportation (which is \$1,2 a ticket) because he has a waiver for handicapped people.

Pino also spends his time doing official procedures and inquires about possible new subsidies, bus passes, pensions, and housing programs for him and for other ex-patients. He is very friendly, everyone knows him and he knows everyone's life. One of his main activities is visiting ex-patients. Rodrigo and Celeste sometimes invite him for lunch, and he was invited to Rodrigo's birthday in January. He also visits María, Sofía, and Dolores in their house, and other *casas de convivencia*. He knew his present girlfriend at a literary workshop at the P-DH; she is separated from her husband and lives in the city with her two sons. He had another long-term girlfriend before, from the Hospital, but she died. He says that he is upset when people still ask him whether he married her or not.

Pino was born in Spain, and he has no relatives in Argentina. Recently, a cousin from Spanin, not seen for thirty five years, came to visit him at the *casa de convivencia*. She knew that he was interned at the Hospital and went there, but at the Hospital they gave her Pino's new address. She encouraged him, with the help of the professionals from P-DH (where he is presently having his therapy, derived from the PSRC), to request a pension for disability from Spain. He receive from the Spain embassy an amount of money that he saved in a bank, and

he is working on a pension for life. He had to prove that he was not receiving any other subsidy from Argentina, but he says that now he has applied for the “national pension” (for disability) in Argentina too. None of these pensions is very much money, anyway, and the work as a seller improves his income just a little bit.

Pino, who has been living at the *casa de convivencia* for more than two years, has projects to move out. Some years ago, still living at the institution, Pino received a small inheritance from a relative from Spain and bought a lot that belonged to a Hospital waitress and is close to the institution. He plans to build a house or buying a pre-fabricated *casilla* (cheap assembled house) and put it on his land, and go to live there with her girlfriend and her children. Pino also applied to a social plan that gives pre-fabricated *casillas* to people in need, and in case he gets that house he plans to put it in his lot too and rent it in order to have an extra income. Pino does all this transactions with the advice and accompaniment of the professionals from Clovera.

Mariano is much less sociable than Pino, and he says that he does not want to know about other’s business. He says that he has nothing to do with the PSRC any more. He is unconfident about doctors, and does not have as other ex-long-term patients a benevolent view toward the Hospital. He goes to the psychologist in “Acute” (where the Hospital external psychiatric clinics are) and he is treated at the external clinic of the neurological ward. He receives his medication at the Hospital pharmacy once every three months (other patients go every week to the PSRC for it). But until recently her girlfriend was interned at the PSRC and he visited her there.

Mariano works in a bakery workshop at the disable s’ Integration Council of the city, where he cooks food by request. He had this activity since he was interned in Clovera, and he used to sell the products too. He had a “plan” when he was at the Hospital but he lost it (these social plans, since they are not formally planned for patients or ex-patients, are not a secure source of income). Besides his job at the bakery, where he does not receive a monetary salary,

Mariano did not have any income when he went to live at the *casa de convivencia*. Now, he has recovered the “plan” (around \$150 pesos) and is waiting for the “national pension” (for disability) as most other ex-patients. Mariano does not have contact with his family, but he gained a father in law (as he calls his girlfriend’s father, from who he talks kindly). His girlfriend Ester, who was still in the PSRC when I did my fieldwork, had introduced him to her father, and they got along very well. “I talk to him by phone, and when I want to, I visit him”. He was planning to move independently with Ester, and they had already rented a house, but they had to wait until the woman living there leaves the house. It is a house close to the Hospital that belongs to a nurse, and they will have to share the bathroom with her. They will pay her \$200 plus electricity, which is affordable by them because Ester also has a “Plan” and receives \$150. Mariano showed me all the things he had accumulated waiting the day he would move with Ester. His bedroom was full with a gas stove, a fan, shirts, a quilt, dishes, pans, a heater, a T.V., and a mattress (a gift from Marcos’ girlfriend, the woman with whom Marcos, and ex- *compañero* from the house, went to live with), and Mariano told me that Ester had a clothier at the Hospital. In January 2006, when I visited the Hospital again, I knew from other patients that Mariano had already moved with Ester. Julieta, a professional from the Hospital, told me by e-mail that they went to see Mariano and Ester’s new house, and that

“even if it is humble, it is so tidy and they enjoy it so much that you feel like you are entering a mansion. By the way, they received us with a dip and even a lighter as a souvenir! I can guarantee you that we are not used to such bustle at the manicomio (madhouse).”

Pedro goes frequently to Clovera because his girlfriend Iris is interned there; he also goes for his therapy to “Acute”, not to the PSRC any more, but he goes there to Pick up the food supplies for the week. I saw him a couple of times carrying bags with food supplies from the Center to his house, accompanied by Pino. Pedro arrived to the *casa de convivencia* in June 2004, and since then his main preoccupation has been to find a job. As Mariano and

Ester, he also has plans for the future, which include moving with Iris. Iris was interned at a regular ward but when I went back to the field in January 2006 she was already living at the PSRC. To be there gives patients a big chance for leaving the Hospital, and Pedro and Iris knows that and is waiting for that. Pedro is always worried about jobs, and he is always looking for a one. "I know that it's difficult that someone would give me a job, because I'm 50 years old," he says. He got a job in a car-wash shop where he omitted to say about his recent *externación* from the Hospital; the job was 12 hours a day for a small percentage of the price of each wash. But he only got the job for two days. Pedro says that it was because the owner wanted someone with more experience and faster. I think that another thing could influence the owner's decision, even though Pedro did not link that thing with his fire: a letter from his Doctor that he showed to the man saying that he was OK and had been *externado* from the Hospital, and in the back of the letter he added that he has to go to the institution every Thursday morning to pick up his medication and for treatment, and that it was possible to call the Hospital and to talk with Dr. X for any doubt.

He looked for a job, with no luck, door by door in all the stores close to his apartment and also in the main street of the town next to the institution. He got a job in a strawberry harvest in a field close to the Hospital, but he quitted because the working conditions were not good, he did not receive any food allowance and there were no bathrooms available. He only received half of the pay when he quitted. After that he applied to a work pool for people with disabilities, and also to the private cleaning company that operates the Hospital cleaning. He participates in a carpenter workshop at the CFL (Labor Formation Center) in the Hospital. He has been looking for jobs in carpenters and also in a construction work, but unsuccessfully. He says that he wants to finish high school in order to have more possibilities to find a job. Pino recommended him to go to the Pre-Discharge House to look for a job, and he went. "I went to the Pre Discharge house to offer me for any job, and they told me that I might try as a seller. I started yesterday and I sold eight of ten floor clothes and two of ten kitchen clothes. I

go door by door, and they give me 10 or 20 percent of the sales,” he told me. He seems optimistic regardless all the failures in his search: “We should make a decision: to go out and start selling. People should be well treated, they are all potential clients.”

Pedro is divorced and has a son but he does not see him any more because he did not receive him well. His brother, who lives in another city, is legally in charge of him (because of a lack of sanity, I believe), and Pedro says that he receives a pension but his brother does not give the entire pension to him, just a very little. When he was interned in Clovera only his mother visited him, and since she died he did not know about his family for a long time. Now he sees his brother when he goes to receive the money and for the Christmas and New Year celebrations. He also has a sister living in another city, and he went for the first time with Iris to spend Christmas at her house last December. They went for three days, and that was the first time Iris had gone out from the Hospital.

Daniel was the last one to arrive to the house, in May 2005, just when I started the fieldwork for this thesis. He says that he chose a *casa de convivencia* instead of a *pensión* because *pensiones* are depressing. He continues his psychological therapy at the PSRC, but he has a definitive discharge. He works at the Day Center from Curaduría (the judicial system) because he is represented by a curator and receives a subsidy from Curaduría. Daniel is the only one at the house without a girlfriend. He was married and has two sons 21 and 17 years old. The last time he saw them was in 1998. He says that his marriage was a disaster and that he never had a good time with his family, he had a bad time. He says that his experience was so bad that he does not want to have anything to do with girlfriends and wants nothing with his family. Only his mother understood him and considered him and his problems. He wants to get alone by himself, “I have to say: I manage my life.”

As well as the women, the four men at the *casa de convivencia* are connected to the Hospital networks for most of their activities, material resources, medical treatment and social-affective life, even though this reliance on the Hospital has different levels among all of

them. Different from other studies that show women as not working and men as having a differential access to temporary and casual work (Wilton 2004 and other studies mentioned in his article), I did not find a difference in this regard. María and Sofía, as well as Celeste or Ayilin as we will see, search and find paid jobs as well as the men, especially through their Hospital connections. However, there is a difference between the men and women of the *casas de convivencia*. The men show a greater degree of independence and reliable plans for their future (in Mariano's case already concreted) than the women (older and with more years of internment). They also spend more time in the streets and outside activities than in the house and in the Hospital. None of the women from the *casa de convivencia* talked to me about their projects for a future, but all the men (except Daniel who had recently moved to the house) talked to me about their projects. Meanwhile, living at the *casa de convivencia*, Mariano summarizes what he and his *compañeros* feel saying that "overall, we are O.K."

### **Life at an Independently Rented Room in a *Pensión***

Living in a *pensión* room is different from living at a *casa de convivencia* in many aspects. People live there alone and not with other ex-patients or *compañeros*; it is an ordinary housing facility where other poor people also live (and not just people labeled as mentally ill); a *pensión* room is not supervised by the Pre-Discharge House, and ex-patients who live in *pensiones* have to be able to afford paying the room because the Hospital does not pay for that. It is less expensive than renting an apartment or house, because it is just a room without private kitchen and in some *pensiones* without a private bathroom. Moving to a *pensión* may be the next step for some ex-patients who are living at *casas de convivencia*, because it implies a greater independence. Ex-patients who have the money at the moment of being *externados* from Clovera may go directly to a *pensión* instead of going to a *casa de convivencia*, but some of them, such as Daniel, are afraid of living alone in a small room and they prefer, at least for a while, to move with others to a *casa de convivencia*. Others, instead,

do not like the idea of sharing a house with other ex-patients and they do not accept to leave the Hospital until they can go to live alone. Ayilin was one of these persons.

### **Ayilin**

After more than 21 years interned at Hospital wards Ayilin spent one year and a half in the Rehabilitation Center, and then she went to live in a *pensión* around March 2005. When she was at the PSRC she received an offer to go out to live with María and Mercedes in a *casa de convivencia*, but she didn't want to go. She does not get along with Dolores ("she does not get along with anybody!" other patients told me) and she wanted her own bathroom, because she says that she is very hygienic. She is very happy of living alone in her own room:

"I like it here because I can mobilize by myself, I can take a shower, or clean the floor, all when I want. What I most like here is that nobody comes to tell me: Did you leave the bathroom clean? Did you do this? Did you do that? and also I don't have to tell anybody what I'm doing, and I can sleep all the time I want."

The *pensión* is located in the center of the main city, in a professional middle-class neighborhood where there are also public buildings, offices, parks, and stores (stylists, videos, *kioscos*, fruit stores, bakeries, book stores, among many others), and less than five blocks from the commercial center with cinemas, theaters, restaurants, and fancy and deluxe cloth stores. The center of cities in Buenos Aires (the downtown) are different from common downtowns in American cities where there are only governmental buildings and offices, with few houses and almost none stores.

The *pensión* is around seven miles from the Hospital, but just half block from the Pre-Discharge House where Ayilin takes all her meals. Other ex-patients from Clovera live in the *pensión*, together with other people. Ayilin's room is in the third floor, crossing narrow corridors and taking different stairs. The place seems very secure, since the street door is always locked and Ayilin has a key for that door, and her room door has two locking systems.

Ayilin's room is around nine by nine feet and there is a private small bathroom. Ayilin has a night table and clothier that she brought from the institution and that she keeps locked

with padlocks as Mercedes does and as patients do in the Hospital. When I asked her about it, she said that “it’s a habit that I got in the hospital.” In the room there is a narrow single bed with a thin mattress, one chair, a one-person table (two by two feet), and a humid and old closet that covers one of the walls. There is one small window without curtains and a bulb light hanging in the middle of the roof. At the bathroom there is a small sink, WC, and a shower. She used to have hot water there, but recently she did not have any more, and she has to use another bathroom shared by others in order to take a bath. She says that before taking a shower she cleans and runs the water, and that she uses plastic sandals. Ayilin does not complain about that, or about the large fungus spot that cover a large part of a wall. She does not complain, either, about not being able to use the *pensión* kitchen, or having to pay \$2 for heating water (she does not pay because she goes to the P-DH for that). When I asked her about her room she always says that she likes it. But one day she told me that her doctor says that as soon as she starts receiving the national pension they will find a better *pensión* or a little house for her. She really likes the idea.

There is no heater or fan in the room, and it is freezing there in winter and terrible hot in summer. I barely could stay two hours in Ayilin’s room in winter during my visits in June-July, because I started trembling. She has a better resistance for that, but she says that sometimes she does not have dinner and goes to bed at three in the afternoon and stays in bed until the next day, because she is warm only in her bed. From my point of view she did not have enough blankets, just two thin ones and no coverlet, but she said that she puts her coat over her feet and that it is enough for her. In summer (January) when I visited her again, she had moved her bedroom to the wall next to the window, because she said that it was fresher. But she could not open the window too much because of the mosquito.

Ayilin has no TV or music system, and her small radio is broken. The room is very silent. In general, from my perspective, the room was depressing and I would feel terrible alone and bored there, not only in her room but in the whole *pensión*, dark, narrow, old, and

austere. But Ayilin is very happy with her new life, she has a positive spirit, and her loneliness does not seem to be a problem for her. She has the privacy she wanted and a private bathroom especially valued by her. She has added some personal elements to her room: a painting (made by the owner of a *kiosco* who gave it to her as a gift) is hanging on the wall; a decorative pink thread carpet is on the table, with little candles; and two little ornaments are glued in the closet doors, all gifts from her teachers from the Integration Council. There is not too much, but they give the room a personal touch.

Ayilin only complains about the lack of money for buying all the nice things that she sees on the streets, especially cloth. She has a lot of cloth but it is old and out of fashion. She has one of the “plans” (“*barrios bonaerenses*”) described in chapter two, and she spends it completely paying the room at the *pensión*. She does not have any other income except for the overdue payment of two years of the *peculio* that she was receiving at the PSRC from the Health Ministry for working at the institution. That was a temporary income until the debt with her was canceled, and the doctors were giving her small amounts of this money when she requested it each week. They recommended her to save money in the Hospital “bank”, and she did so with part of the money. The professionals at the PSRC are always concerned about ex-patients managing of their scarce money, and they keep some degree of supervision over their expenditures. In January 2006 Ayilin was waiting for a social worker who will inspect and recommend her for the “national pension” (for disability), which is \$280 instead of the \$150 of the “plan”, and is for life. Meanwhile, Ayilin is worried about losing the “plan” and having to return to the Hospital because she would not have money to pay the *pensión*. She told me that she talked with a nurse from Pre-Discharge about that, and that he told her that they (the health workers) would find something. She likes the idea of working with a family, but she says that she is not ready yet, that she needs to “rehabilitate” more. “In order to be with people I have to be better, I have to be more agile and to be able to bend down to clean. I

will know when I am OK. I have to have rhythm again, and I have to be in good spirit,” she says.

Ayilin does not see any of her relatives, and she does not want to have a boyfriend; she does not like men too much, especially patients and ex-patients. Everybody knows her at the *pensión*, but she says that she does not talk with anybody. The owner of the *pensión* knows that Ayilin comes from a psychiatric hospital, and she knows that Ayilin may be at the PreDischarge house if she is not in her room. But she is not responsible for her or for giving to her the medication, which Ayilin manage herself. “I have never forgotten to take the medication” she told proudly and even challenging. Ayilin has her medication on the night table, five different types, “but just one psychiatric, the others are for my bones”, she explains.

For Ayilin, cleanness is an extremely important issue; she is proud of her cleanness shows her ability to clean as her best capability. She wants to show that she is able to manage her personal care and to care of her room, and she call the attention toward the washed floor, the carefully closed trash gab, the deodorant for the ambient, her clean hair, etc. Ayilin enjoys cleaning her room and washing cloth. She spends lots of time doing that. She buys cleaning products and she has several washbasin, disinfectants, perfumes, deodorants, and floor cloth that she buys with her money. She also bought a rope that she handed up from one side the other of her room (you have to bow for passing) where she hangs the cloth she handily washes in the bathroom.

Most of the activities Ayilin does outside her room are related to institutions, but not only to the Hospital. Se She goes every day to artistic classes at the Integration Council for disable people in the city<sup>52</sup>, where she takes music and bijou classes. One Saturday a month she goes dancing with the people from the Council to a disco, and during the summer, when there are no classes, she goes with them to a club with a swimming pool. Ayilin also goes to

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<sup>52</sup> Not a mental health facility but a devise for all disable people run by the government of the main city.

the Pre-Discharge House to have all her meals (the PSRC does not give to her food supplies as other ex-patients because she does not have a kitchen there to cook). IN spite of the fact that she is not a P-DH patient and she is still treated by her psychologist and psychiatrist at the PSRC, she spends a lot of time at the P-DH. She does not go there to socialize with other patients or ex-patients, as other people does, but to stay there, talk with nurses or health workers, heat water for her mate or powder milk (she has a thermo that takes to the *pensión* with hot water) or to ask the workshop teachers for activities such as schooling homework (joint by arrows; this number is bigger than...and smaller than...; syntax exercises, make sentences, make additions, draw, etc.).

Regardless her lack of monetary resources, Ayilin has found some strategies for living. An important one has been establishing good relationships with the owners or employees of the stores in her neighborhood. She asks at the laundry for free cloth washing or offers to pay later, she has cut her hair for free because of her friendship with the stylist, and the employees there buy the bijouterie she makes; the man at the fruit store gives her apples for free; the man at one of the closest *kioscos* gave her some crochet needles, and he also gives her things that she can pay him later. When she makes bijouterie, she walks the nearer streets trying to sell it, and she also sells it at the Hospital. When she runs out of money Ayilin asks nurses at Clovera and the P-DH or teachers at the Integration Council for toilet paper, powder milk, soap, shampoo, and other products.

When I asked Ayilin whether she has friends, she mentions her teachers or myself. She does not receive visits and does not want ex-patients to visit her. She only likes to stay with nurses or teachers from the Integration Council or the Pre-Discharge House. Especially at the Integration Council, where she has been going for many years and is in much esteemed (she goes there since she was interned in a regular ward in Clovera Hospital). One of her teachers even invited her to spend Christmas with her family. Even tough she does not receive visits she knows how to do all the things people typically do with a visit. She offered me a sit,

offered me *mate* or something to drink (or offered excuses if she did not have any), and she hold my arm and accompanied me to the street door or even to the bus stop. She is very happy when I visit her, and she talks about her teachers at the Integration Council with enthusiasm too. She just does not want to have a relation with people with psychiatric problems. This is different from persons as Pino or María, who enjoy visiting ex-patients, or as those having girlfriends/boyfriends from the Hospital.

Even tough Ayilin has made good relationships with owners or employees of near stores, she says that she does not like too much to go the B street (the more fancy commercial center, with cloth stores) because people stare at her, and she told me that once she entered a shoe store to buy some shoes the employee stopped her at the door and ask her whether she would buy or not. This situation was not reported by any other of the ex-patients who participated of my research, because in neighborhood's stores people do not dress different from every day cloth, and it is also common to see poor people buying or asking for food/money. But people dress especially well for going to the fancy commercial center zone of the main city (where Ayilin went and close to where she lives), and poor people do not buy there because of the expensive prices. Ayilin appearance is not bad, but she is probably out of context there; she does not fit or pass unobservant as she would in other stores and neighborhoods.

I found that Ayilin, who besides her schizophrenia has been diagnosed with moderate mental retardation, has good self help (*autovalimiento*). She manages the cleaning, her time schedules for classes, workshops, and meals at the P-DH very well. She walks around fifteen blocks to the Integration Council being careful in crossing the streets and she does not get lost in the city. She takes the bus to the Hospital, she pays her debts with the different *kioscos* that allow her to buy and pay later, she does not spend her money in unneeded cloth or expensive things, she has always some food (apples, tomato and mayonnaise, cookies, powder milk) in case she does not want to go to dinner to the P-DH or in case she is late and there are no more

food there, she keeps all her documents and important papers under lock and carries with her, some money, her bus pass, her DNI and other important things; she takes her medication three times a day, she gets up in the mornings for going to early classes, she keeps the street and the room's door locked, and she never goes far or goes out in the night. "Here says that I have mental retardation, but I almost had it. Because I would not be able to live alone if I had it, don't you think?" "My problem is all psychological," she told me.

Regardless her self-help (*autovalimiento*) and also autonomy for many things (she asks for things she need, she manage money, she pays her debts, she sells bijouterie when she needs money, she goes shopping alone, etc) Ayilin keeps some habits from the institution, such as insisting in keeping nurses or somebody from the Pre-Discharge House informed about what she is doing, where she is going, etc., or feeling that she has to ask for permission. She is always thinking in what is she going to tell her psychologist, and she may not be able to live without certain dependence from institutional support, such as the P-DH pr the Integration Council, which make her feels protected. Different from other ex-patients, she did not make friends with other patients at the Hospital, and she does not visit anybody there. But she keeps a strong tie with the health workers, from whom she feels secure and cared.

Ayilin says that "it is not easy to leave a hospital to live outside. It is easy to be in the hospital, where you have everything served. But I don't like that." She remembers her life at the Z ward as a good life, where she took care of the *viejitas* and had always something to do, but when I asked her if she would like to go back to her old ward, she convincingly says no. She has the same contradictions pointing out by Edgerton (1967) for mentally retardate patients at hospitals. According to this author, being at the hospital allows the less retardate patients to aggrandize themselves and reconstruct their damaged self-esteem by comparing themselves to manifestly severely retarded patients, but at the same time they feel uncomfortable because they say that they do not belong there. Ayilin liked the Z ward because she was the only one who could do the same work that nurses ("normal" people) do,

but at the same time she said that she was wasting her time, that she did not have to be there, that she could live alone. And she strongly prefers to live in the pensión than at the Hospital.

### **Life at an Independently Rented House: Celeste and Rodrigo**

Celeste and Rodrigo rejected previous possibilities for *externación* from Clovera because they had one firm objective in mind: to leave the Hospital together as a marriage. When they say “we are the pioneers” they are very proud that they finally achieved it. In January 2005, after 34 years of hospitalization her and 20 him, they rented a small house in a low-income neighborhood and moved out. A few months later they received the final and complete discharge from the institution. Renting a cheap house independently from the Hospital is the only possibility for moving out together, and doing that they created an option for other couples (Mariano and Ester, Pedro and Iris) who wanted to do the same.

When Celeste and Rodrigo left the Hospital they had only a “plan” each one, of \$150 Celeste and \$120 Rodrigo, and renting a small apartment in the center of the main city or in urban neighborhoods can be around \$400. Therefore, they searched for more modest houses in low-income neighborhoods such as the ones that surround the Hospital, and they rented a small house in the backyard of another house where a woman and her four daughters live, and where they have to pay only \$100 a month. Those neighborhoods are in zones in between rural and sub-urban (*región rural periurbana*, Archenti and Ringuet 2000). Sub-urban neighborhoods in Buenos Aires are different from American Suburbs, as well as the center of a city (downtown). American suburbs (middle class neighborhoods with no stores, public transportation, and other services and facilities, where everyone has a car) are reproduced in Argentinean “*barrios cerrados or privados*,” (enclosed or private neighborhoods). But most suburbs in Buenos Aires are inhabited by lower middle class or low income people with or without a car, and there are many stores where people daily buy what they need instead of driving to a supermarket or a shopping mall far from the neighborhood. Usually, there is also a playground and fields used for playing soccer, and many streets are made of dirt.

The objective material conditions of Celeste and Rodrigo's house look terrible compared to Ayilin's room in the city. They do not have water inside the house and have to pump it manually outside and carry it in buckets to the kitchen and bathroom. The walls have many holes and when it rains the roof shows leaks all around the house. But the house has something warm that makes it appear comfortable. "Erica and Martín are invited by the Fernandez family to our all-you-can-it place, and they are doubly welcome," wrote Celeste in a card that she made and give to me at the entrance of their house on August 2005, when my husband and I were invited for lunch as a good bye party. Different from the austere and cold *casas de convivencia* and from silent and hotel-like Ayilin's *pensión's* room, it looks like a real home. Celeste and Rodrigo talk about themselves as a "marriage" (even tough they are not legally married and Rodrigo was legally married with another woman), "we have been eight years together and now we wear silver rings instead of the tin ones we had" says Rodrigo. "Look our son," says Celeste showing a fat small dog who has a bed made of old cloth in their bedroom. Celeste also refers to her new dog as her daughter, and she put the last name that she and Rodrigo have to her: "my *perrita* (doggie) is *Estrellita Fernandez*. For me she is like a girl, the girl that I never had. She sleeps in our bed and we love her very much" wrote to me Celeste in a letter (April 2006).

Celeste and Rodrigo's house is a square divided in four parts, made by brick and wood. The brick part, in the back of the house, has a corrugated metal roof with wood planks covering inside that includes the bathroom and the dinning room; there is no plaster or painting on the walls but there are no holes. The wood part is the kitchen and the bedroom, in the front of the house, and it is full of holes and leaks. The floor is made of concrete, and it is wet in some winter days because humidity spring up. The house has two windows with curtains. The bathroom has an electrical water heater connected to the shower, which is filled handily. In the dinning room there is a table with four chairs, a refrigerator, a sideboard, a chest of drawers, and a cabinet. In the cabinet Celeste has things that she collected while

being at the Hospital, such as a table cloth, dishes, napkins, a bread plate, and all the things needed for serving a dinner. “I started to collect them long time ago, for the day I have my house,” told me Celeste. The kitchen has a gas stove and wood fruit boxes creatively used as tables or stools. They do not have water in the kitchen, but they go outside to use a faucet and to wash the dishes and cloth there. The bedroom has a big and old clothier, a double bed, a TV, and other fruit boxes as night tables. They have also a bed for one of their two dogs in the bedroom and another one in the dining room. The house is decorated with plants, cigarette boxes (ones with pictures of cars), posters, and a small Christmas tree in December. Celeste also has some plants in pots outside the house. There is no heater for the winter, and they say that they sleep with five blankets. In the summer, they open the windows and the door and the air goes through the house, keeping it fresh. In general, the house looks like any other house of humble people in Argentina.

When they were still at the PSRC planning to go out they bought a used color TV and a used refrigerator from a nurse from Rodrigo’s ex ward who has a thrift shop close to the Hospital. The refrigerator broke, and the chief nurse from Celeste’s ex-ward gave to them another one when she received a new refrigerator in the ward. The Hospital gave them the stove, and Solo, the director of the Theater, gave to them chairs and a table (from the Hospital theater). They bought other things that they needed, such as stereo and a mattress in another cheap place recommended by a neighbor. The Hospital gives them the food supplies every week, and they have to buy the cleaning and bath products.

“Sorry for the poverty; the house is small and humble but the heart is big” told me Celeste when I entered her house for the first time. She and Rodrigo, but especially she, expresses their emotions all the time. Celeste wrote me a letter in February 2005, after one month of living in the house, in which she says that “we are fine or, better still, we are swell and very happy. I still can’t believe that God gives me all this joy.” The neighborhood is a typical humble neighborhood in the periphery of south American cities, with dirt streets,

many houses under eternal construction, empty lots, and houses made with different quality of construction material, from brick to wood or metal sheets. Some houses look nicer than others. The house in front of Celeste and Rodrigo's house is made with bricks and looks in good conditions. A woman divorced from a policeman lives there with her four daughters of 5, 9, and 12 year-old twins. She is the owner of Rodrigo and Celeste's house. She is around 40 years-old, and they call her "*la señora*" when they refer to her. The access to Celeste and Rodrigo's house is through the parkway where there is no car. Across the street lives Karina, a young woman who works at Rodrigo's old ward as nurse assistance in exchange of a "plan" that she holds. She lives there with her three sons. Rodrigo and Celeste found the house because of her, when Rodrigo heard her talking about a neighbor (*la señora*) renting a little house in her backyard.

There are always people in the streets, especially children playing but also men fixing old cars or people walking or biking. Two blocks from the house a bus stops and it takes just ten minutes to go to the Hospital. Celeste and Rodrigo say that they do not have any problem in the neighborhood, in part because they are most of the time inside and because many people working at the Clovera Hospital lives there, such as two nurse's assistants and a gardener.

Recently, Rodrigo and Celeste got the National pension and a subsidy for *externación*, which increased their income, and their doctors suggested them to rent an apartment in the city instead of living in such a poor house, but they did not move from the house. Rodrigo explained to me that they do not have the guarantees required and they do not have all the money they ask in case you do not have a guarantee, either. In addition, they prefer to stay in the little house because they already got affection for the girls who live in front, and they like to live in a house, with plants, with the possibility of having the door opened for the fresh air to enter.

Celeste and Rodrigo spend a lot of time at the house together, drinking *mate* and watching TV soap operas. Roberto does the cooking most of the times because he used to work

as a cook assistant in a restaurant. He taught Celeste to make some easy foods, but he cooks most of the times, and Celeste washes the dishes and the cloth. Sometimes at night Celeste asks him what he wants for dinner, and knowing that she has not good skills for cooking he asks for something simple: “*churrasco* (grilled steak) and salad.” Celeste prepares the medication for both in the afternoon, and Rodrigo prepares the medication in the morning and in the night. They say that they are used to take it because they have done it for many years. Celeste feels protected with Rodrigo, who has more experience living outside the institution than her. She says that she would not know how to go to Buenos Aires city and to move around as she does with Rodrigo, because she had never been there before, but Rodrigo deals with the city very well.

The *externación* from the institution does not mean that they are not linked any more with the Hospital. As all the other ex-patients *externados* through the new programs (PSRC and P-DH), Rodrigo and Celeste continue receiving psychiatric treatment and psychological therapy at the Hospital PSRC for that. Rodrigo told me that soon they will be derived to the external psychiatric clinic in the Acute sector of the institution, because “*we are now ambulatory patients.*” Food supplies and treatment are not the only reasons to go to Clovera Hospital. They also have contact with the institution for social reasons, since they have lots of friends there, and they are very appreciated by patients and personnel. Their previous pet is still at Clovera, where a friend is taking care of it. They have friendship relations with other ex-patients, especially with Pino, who visits them frequently and they also invite patients from the PSRC to have lunch at their house. They always talk about Mariano, Ester, Pino, María and other ex-patients that I do not know but they want to introduce to me one day. They also have constructed other social relationships and are engage in other activities not directly related to the Hospital.

When they moved to the house they only had the “plans”, and there was not much money left after paying the rent. Both of them smoke, and even though they buy the cheapest

cigarettes available they spent as much in cigarettes as in the rent of the house. Therefore, other strategies to make some extra income were necessary. Rodrigo used to make pop corn and sell it at the door of near school until the director of the school did not allow him to do it any more; he also went to sell pop corn to a relatively close stadium, during a concert; he also did jobs at the Hospital such as picking up the white cloth (sheets and towels) ( a task assigned to him personally by the Hospital Director in order to have some control over the thieving) or selling the products from the hospital farm at a post inside the institution. He received ten percent of the sales (he made around \$15 pesos per week) plus \$20 a month.

Another type of strategy included a performance in order to travel for free when Rodrigo and Celeste did not have free bus passes on Saturdays: in two or three occasions Rodrigo stopped the bus saying that his wife was sick and he had to take her to the Hospital but they did not have money; and Celeste acted as if she was sick. Later, Pino recommended them some proceedings to do for obtaining free passes every day in any bus. Celeste also had found sources of improving their income. Once a week she washes the cloth of a man interned at Rodrigo's ex-ward whose sister pays her \$50 a month. "With the washing and the sales at the farm post we pay the rent; and we have left \$275 from the two plans, but we spend \$100 in cigarettes. It is vice that we cannot leave" told me Rodrigo. Celeste also works cleaning the house of a known nurse from her old ward, and she is expecting a job at company in charged of the cleaning of the institution.

Rodrigo and Celeste manage well for finding money, especially through their Hospital relations, beyond the low income from their social "plans." When I saw them again in January 2006, however, they did not have the "plans" any more and both were receiving the "national pension" and the new subsidy for *externación* from the Health Ministry, and they were making together more than \$1000 pesos a month. With that amount of money, Rodrigo told me that he will not work selling the farm products any more, and that he will give the job to

another patient, because it was no significant money for him now. He is not worried about finding jobs any more.

Other activities that Roberto and Celeste do are social and religious. They go to an evangelic church, and on Saturday afternoons they go with the pastor and other members from the church to the Hospital to predicate and to offer some especial foods to the patients. They do that in the Hospital theater, allowed by Solo (the Director of the theater), who knows very well Rodrigo and Celeste. Rodrigo told me that the Director of the institution was not convinced about that, and he did not say yes to them, but he did not say no either. Rodrigo knows that the patients who participate (around fifty), especially the men, go there because of the *empanadas*, *tortas fritas*<sup>53</sup>, and hot chocolate that they give to them, and not because of their interest in the God's words; "they (the church people) think patients go to listen God's word, but I know they go just for the food. But I understand them because when I was at the hospital we never eat *empanadas* or *tortas fritas*." Celeste and Roberto contribute with the flour to make the *tortas fritas* and also chocolate powder from the food supplies that PSRC gives to them.

Going to the Hospital Theater is another activity that they do. They have been acting there since several years ago. Rodrigo accompanies Solo, the director, to the main city and to other cities asking for places to present the play. Another activity they have is visiting people. Rodrigo visits his old ward and talks with the patients and the nurses. I knew about Rodrigo going with Solo to the near prison to visit a former Hospital patient who used to act in the Theater. Celeste and him also visit church members at their houses, as friends, and they are visited by them too. I met a woman from the church drinking *mate* with them one day when I went to visit them at their house. Occasionally, they visit family members: Rodrigo's father, who lives in another city relatively close, or Celeste sister who lives even closer. For the New

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<sup>53</sup> *Empanadas* is a traditional food made of half moon-shape dough filled with chopped meat or other ingredients and baking or fried. *Tortas fritas* is a traditional sweet cheap pastry similar to the French *bignie*, that is not sold at bakeries but it is made at home.

Year celebration they went to Rodrigo's son's house at the beach and spend a whole week there. "We spent \$600 pesos", they told me proudly because they bought candies and gifts for their grandchildren (Celeste has adopted Rodrigo's grandchildren as her own). But even though they like to tell about their family they have no regular contacts with them, Celeste told me how sad is Rodrigo because his son does not visit him, and how sad is she because her brother does never call or visit her. They have constructed a new relationship with some of their long term lost relatives, but they do not depend on them for their living.

Celeste and Rodrigo also spend time with "la señora" and her daughters, and with the woman and children living across the street. I saw them watching TV in the house of *la señora* with the children, and Rodrigo told me that they go there frequently. They spent Christmas with them, and Rodrigo prepared *empanadas*, *chorizos* (sausages) and chicken in a barbecue. They go to watch important soccer games at Karina's house because not all the channels work in their TV. They also take care of the girls. "Yesterday night we were babysitters; we slept at the house of *la señora* and we cooked there for the girls, because she went out with her sister" told me Celeste and showed me drawings that the girls made for her and saying "Cele you are super cool with us. I love you with all my heart;" "it was strange when you came here, but you are very nice and kind, and we love you very much." Celeste says that "they are like a family for us." The children visit them at their house and sometimes they take the "*merienda*" (afternoon milk and cookies) there. On Sundays Celeste and Rodrigo take one of the girls each week and go to different places in the close city and in Buenos Aires city, such as the zoo, the Government house, a park, etc. "We only take one girl with us at the time because we spend a lot of money. We pay the bus, a hotdog, and other things they want. And also because it is dangerous to take all of them, it is too much responsibility."

Even though their house has an independent entrance by the side of the *la señora's* house, one of the girls, *la señora*, or a boy who is always there receive any visitor before he

reaches Celeste and Rodrigo's door. They always intercept me at the front and then run to call Celeste and Rodrigo, as if they were living together. The girls enter Rodrigo and Celeste's house all the time asking for things such as a pen or a lighter, or asking for help. It is obvious that *la señora* relies on them for the childcare and also for other help. One day that I was with Celeste and Rodrigo a friend from *la señora* arrived when she was not at home, and the girls asked Rodrigo what to do. He went to receive the man, made him sit, prepared *mate* for him and told him to wait there. Celeste and Rodrigo are always thinking in the girls. One of the days they invited me for lunch and I brought strawberries for dessert, and Rodrigo took some to the girls who were in the other house. Celeste told me that for the children's Day she asked at the Hospital for milk, and she made chocolate for the girls and also Karina's children. They share the food supplies received from Clovera, which is too much for them, with *la señora*. She gives them some material things too, as her washing machine, which they pull out to the yard for using it there (it is a small and round old machine), and she allows them to use her home telephone. When somebody phones them, *la señora* send one of the girls to tell Celeste or Rodrigo to come to the house and pick up the telephone.

Rodrigo and Celeste have big projects. They told me that they would like to adopt a child, not a baby but an older one, when they receive the house from the Governor (the one that they are in the waiting list). They also want to travel to Celeste's natal province in the south of the country, where she does not go since she was less than fifteen years old, and where she has family that she wants to know, especially grandnephews. They were planning to go for Christmas, as a surprise for her family, and they were finding out how to apply for receiving free tickets for disable people. They wanted to save money to buy gifts and to invite Celeste's family with a barbecue. "If we don't have the subsidy for December we are not going, because Celeste family is humble and we don't want to be a charge for them, but the contrary, we want to help" told me Rodrigo in August. Even though they received the subsidy in December they did not go yet.

Other more simple projects are buying a better TV, or crossing their new dog, which seems to be of good race, with the one that a neighbor has, and then sell the doggies. Rodrigo also wants to buy a washer machine, so Celeste does not have to bend to wash handily when *la señora* is not at home for lending her the washing machine. Celeste and Roberto have found a new life in which they have projects as those that any other person may have, and in which they are not passive receptors of benefits and directions but rather actively engage in social relationships in which they receive but they also give. And they are very happy. Celeste and Rodrigo use the Hospital as a resource and keep connections there because of affective and (relatively) material needs, but they have an ordinary life and made a very good social integration with people outside the “psychiatric community”(McCout Parring 1993)

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The new life outside Clovera described in this chapter for former hospital patients in Argentina is far from the picture of a life in the community as “lonely, empty, and isolated” portrayed by Davison (1995: 128) for the twelve persons discharged from an American psychiatric hospital in New Haven. The new lives of María, Pino, Ayilin, Celeste, Rodrigo and the other persons of my study are not “unproductive”(in any sense) or lacked of “true” friends and “romantic involvements” as Davison et al (1995) finds for the New Haven ex-patient population. They have been equally long-term psychiatric patients (in the Argentinean case for a mean of even more years) and diagnosed mainly with schizophrenia. Why the different outcomes? Many factors interact in the answer to this question, as we will see in the following chapters.

## **Chapter 5**

### **Integration in the Outside Society**

Deinstitutionalization, from the human rights discourse of the concept of “community based” mental health care, aims not only the location of mentally ill in the community but also their integration as participants of community life. But as McCourt Perring (1993) says, the concept of “community” has been idealized and romanticized by policy planners. As many studies of ex-patients’ quality of life have shown, communities are far from being so integrative (Wilton 2005; Davison et al 1995; Segal and Aviram (1978), among others).

In the case of ex-patients from Egidio Clovera, they find different degrees of social integration depending on the communities (neighborhoods) where they live. They find a more reciprocal position among people who share their situation of poverty, lack of education, unemployment or sub-employment. Societies are not homogeneous or egalitarian, and ex-patients integrate the Argentinean society as part of its more vulnerable population. The issue of integration of ex- psychiatric Hospital patients in the community is mutual: it means how they overcome their institutionalization and are able to have a “normal” life, and how the “normal” people allow them to do it. But what is a normal life and who are the normal people in Argentina society?

A normal life for ex-psychiatric patients may be understood as sharing the things that adult people who are not institutionalized do, such as having a social role, having reciprocal relationships instead of being passive receptors, having the freedom to make choices, or having auto-determination. But due to the fact that societies are complex and formed by multiple social groups, we should not understand being “normal” as the prototype of a middle class people. We should not look at the ex-patients’ quality of life as integrated members of society considering their participation on the competitive industrial market economy and college education, or having and doing the same things middle class does. Usually, middle

class people are not interned in public hospitals like Egidio Clovera. Therefore, very few ex-patients belong to a middle class family in the past, and after twenty or thirty years of internment, anyway, they lose their social relationships, material resources, and even the education they received, and they are now as poor and out of society as the other lower class patients. Ex-patients may feel unfit in a middle class neighborhood not because they are mentally ill but because of their socio-economical status. We have to understand their life taking into account that they may live as many other people do in Argentina, taking a bus instead of having a car, having periods of unemployment or being permanently unemployed but doing *changas* (occasional jobs as employments, or doing autonomous activities for obtaining income) for survival, relying in the solidarity of neighbors or family members for coping with their basic needs, receiving some income benefits from the government, living in deprived houses, having low education, etc. They are *marginals* in a sense of somebody that “lacks a formal articulation or insertion in the urban industrial process of production, and suffers from chronic insecurity of employment” (Lomnitz 1977:13), they are in the margins of official economical and political processes (Lomnitz 1975:17) Marginals are, in Latin America, usually “left to their own devices as far as the business of survival is concerned” (Lomnitz 1977:14), but they may be under social security, as far as they are excluded from the official economical and political power sources (Lomnitz 1975). The ex-patients participating of my research are marginals; none of them have a “productive” work in terms of the market economy. But they have, with respect to other marginal people, certain privileges. They have the Hospital as a source of multiple resources, and they receive governmental subsidies or pensions.

After saying that, I can say that I paid attention to the social integration of the ex-patients from the perspective of marginal people living in Argentina. I did not pretend to measure the level of social integration of the ex-patients with an objective scale, and I did not use a survey methodology. But, from the qualitative descriptions that I made from ex-patients

accounts and my observation of their life in the community, I can say that they have a relatively high social integration in their communities. This integration depends not in ex-patients efforts but on the socio-economical characteristic of the places where they live, being higher in low-income suburban neighborhoods where they are equal to their neighbors.

In various ways, all of them are present in their neighborhoods and use community resources as other people do. All of the ex-patients go alone outside the house and participate in different activities outside too. Many but not all of these activities are offered by the Pre-Discharge House of the Hospital, the Integration Council of the city, and the Day Centre of the Judicial Power, such as the workshops and classes where Mariano, Daniel, and Ayilin go. Other activities are find in their walks around their neighborhoods: Mercedes going to a catholic church, Celeste and Rodrigo going to an evangelist church, Ayilin going frequently to the stylist and to other shops where she also offers the bijouterie she sells, Pedro trying to find a job asking door by door in the street, Sofía working with a family who owns a supermarket.

All of them go shopping and take the bus to move from one place to another. Some of them move in different neighborhoods and also go to Buenos Aires city (Rodrigo and Celeste, Mariano and ester, Pino) and others such as Ayilin move only in a more reduced space, from the Hospital to the Pre-Discharge House, to the Integration Council. But they have to walk or take the bus from one place to the other, and they have some interaction with people at the bus stop or the many stores in the streets. They manage the domestic tasks, their money, medication, and schedules without help, but they always have health professionals, nurses or teachers who may give them advice, since none have dropped their treatment.

In general, ex patients have projects as other people do, and they have concerns about jobs and money as other people do too. They interact socially in a new world in which the “inside” or psychiatric sphere and the “outside” world are mixed. They are engaged in social relationships with peers (other ex-patients or hospital patients), with hospital employees

beyond their caregivers job, and in different degrees with family members and people from outside the “psychiatric sphere.” They do not live in an environment of “social poverty” but just in economical poverty, and the “clinical syndrome” described by Wing and Brown (1970) for schizophrenic patients living in a context of “poverty of social environment” (flatness of affect, poverty of speech and behavior associated with social withdraw) are not present among the ex-patients. The neighbors’ attitudes toward the ex-patients vary from indifference to cooperative help, but I did not observe or hear about rejection, a main problem in exclusionary neighborhoods in the United States (Segal and Aviram 1978), and ex-patients did not report any rejection when I asked them about that

### **Neighbors’ Attitudes**

The ex-patients have not reported to me any rejection or exclusionary attitudes from their new neighbors. They say that their neighbors are kind to them and that they did not have problems with anyone. Some of them are still afraid of public rejection if they know that they have been interned in Clovera, and they try not to interact much with neighbors because they do not want to annoy them. In general, the women and men say that they interact especially with store owners and store employees, not with other neighbors, but they recognize that people’s attitudes have changed with time, and that today there is not as much discrimination as in the past.

The pro-patients’ *externación* view is quite new in Argentinean public, and it is especially favorable since the last three or four years, when debates and proposals about mental health policy and legislation changes raised. When I asked them about experiences of discrimination, ex-patients did not point out any explicit and face to face case of rejection, and their first answer was that they are not discriminated and feel comfortable in the neighborhoods. But thinking more carefully they talk about some things that happened to them not in their neighborhoods but in the streets in general, and that may relate to the fact that they are ex-hospital patients. For instance, Pedro could not find a job when he was using

a hospital jacket; Ayilin was stopped at the shoe store entrance and being asked whether she will buy or not, and Celeste was not allowed to vote<sup>54</sup>. These examples show that the stigma of being a psychiatric hospital patient is still present, regardless of the acceptance of the idea of *externación*. During my previous research at Clovera Hospital and Town, I noticed that people who live in frequent contact with psychiatric patients are not afraid of them at all, and that they are, instead, sympathetic. This is not the case of people who never went to a psychiatric hospital and have many prejudices and fears. For them psychiatric patients are an “other” near but uncertain. According to Edmund Leach (1967) our attitudes toward other people depends on the emotions arouse by different categories of relationships between “we” and “them”, “the others”. If the “other” is remote he is not dangerous and is considered mild; in the same way if the “other” is near us (an equal, subordinated or superior) he is predictable and we know what to expect from him. But there is a third category, says Leach, of “others” who are near but uncertain, out of our control, and therefore frightful such as a wild animal. Ex-hospital patients may be seen in this third way for those who are not used to dealing with them, but when their neighbors get to know them, this view changes.

In Celeste and Rodrigo and in Ayilin neighborhoods people do not remain unknown. Besides this fear and suspicion that exists, the sympathy towards patients *externados* and the positive attitudes about their social integration makes the near-uncertain “other” look less uncertain and therefore less frightful. This positive attitude may be explained by different factors, and I did not make a study of that, but an important point may be that people in Buenos Aires know that the patients that are being *externados* are those who “should not be in the Hospital” because they have recovered and they are not dangerous. Argentina has a positive media support of the *externación* experience, different from the United States media

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<sup>54</sup> For first time in her life Celeste went to vote and she felt frustrated and impotent when she was not allowed to do it because it was suspicious that at her age her DNI did not have any previous vote stamp. Rodrigo, who was with her, explained to the people at the vote committee that she has never voted before because she has been interned at the hospital for 34 years. But they thought that maybe she was still unable to have her civil rights. Rodrigo and Celeste had to go to the hospital union and ask a person from the union to speak for them at the vote table. She only could vote after they brought a discharge certificate from the hospital.

that, according to Brown (1985), has portrayed ex-patients as having unpredictable behavior - especially violence- and as essentially aggressive. In Buenos Aires people trust in the hospital professionals' decisions about *externación* and they know, through the media, that those patients are some of the hundreds who remain interned just because they do not have a place to go. They probably would not have the same attitude if all the hospital patients were *externados*.

The neighbors' acceptance of ex-hospital psychiatric patients living in their neighborhoods is not a theme of concern for the professionals in charge of the new programs. They seem to share the same favorable opinion about neighbor's attitudes: that there is not too much prejudice or discrimination, that people show more solidarity than what they expected, and that Argentines are different from the more individualistic and segregationist North Americans. Health professionals from the Pre-Discharge House found a better social insertion of ex-patients living in the neighborhoods, even in middle class neighborhoods, than that of ex-patients living in *pensiones* in the inner city. But in general they have not seen rejections to ex-patients interaction in the community. They point out experiences of good social interaction between ex-patients and their neighbors, such as María, Sofía, and Mercedes asking a neighbor for a hose when they did not have water, or Ayilin selling her *bijouterie* at a hairdresser shop. It is not clear whether these experiences are frequent or sporadic, but what is important is that they are not the exception, because it is found almost in all of the ex-patients experiences with their neighbors.

But the idea that Argentines are considered more social, less individualistic, and more open to solidarity with people with differences may be idealized. It would be unfair to compare the situation there with what is happening in Argentina. In the United States, for example, psychiatric hospitals closed and discharged thousands of patients in very few years, creating a super population of mentally ill in some communities. There was a private community-based facilities market outburst, creating exclusionary attitudes in many

neighborhoods (Brown 1985, Segal and Aviram 1978), and causing the NIMBY (not in my backyard) syndrome (Krieg 2001). Segal and Aviram (1978) describe the public reaction against the mentally ill in the community during the process of speedy hospitals closure and patients' release in the United States. Large privately owned board-and care and nursing homes "hunted" for patients discharged from hospitals and paid by Medicaid. These facilities proliferated in ex boarding houses of university campuses, in deteriorated hotels, and other residential facilities previously used for other purposes but not longer competitive in these other markets, and they "created visible and sometimes problematic concentrations of former mental patients in communities throughout the country" (Segal and Aviram 1978:65). According to those authors, a typical reaction was exclusionary measures to keep residential-care facilities out of neighborhoods<sup>55</sup>, pushing the creation of "mental patient ghettos" or "psychiatric ghettos." According to Segal and Aviram:

The process of ghettoization of the mentally ill, that is, their restriction to certain neighborhoods, may be in part a result of economic conditions. . . Economic reasons are not, however, a sufficient explanation of ghettoization of the mentally ill. Many move or drift to certain areas because their previous efforts to live in other neighborhoods failed (Segal and Aviram 1978:72).

The sociologist Phil Brown also describes this situation in the United States:

Deinstitutionalization has produced other real and perceived burdens to neighborhoods. In the psychiatric ghettos of the major cities, tens of thousands of ex-patients may be found in nursing homes, boarding homes, SROs (single room occupancy hotels), and on the street. Neighborhood residents often feel that these persons are intrusive and dangerous, that they make the neighborhood less pleasant an environment, and that they diminish property values (Brown 1985:141).

We are far from this situation in Argentina, where the immense majority of people diagnosed as mentally ill, especially those who require permanent care, still remain in psychiatric hospitals. We have had neither a massive de-hospitalization nor an extensive

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<sup>55</sup> Segal and Aviram (1978) describe exclusionary procedures such as city ordinances (for example a city ordinance from Long Beach, New York, that prohibited the registration in local hotels of people requiring continuous psychiatric care or medication; exigent regulations that make the opening of a residence facility too complicated (building codes, fire safety, license or quality of care impossible to fill requirements); neighborhood pressures, and bureaucratic obstacles.

opening of community facilities. The supposed solidarity and non individualistic characteristics of Argentines may change if instead of a few ex-patients leaving hospitals we had many of them released at the same time.

Given that neither professionals nor ex-patients accounted for neighbors' attitudes that may negatively affect their life in the community, and given that I did not want to talk with neighbors about ex-patients behind their backs, I only interviewed owners of small stores from the middle-class inner city, where Ayilin *pensión* is. I did not ask about her but about the ex-patients (in general) who live in her *pensión*. Store owners recognize some odd behavior as shouting if the store does not have something wanted but in general terms they say that the ex-patients are "good clients." they say that ex-patients are not dangerous at all and have never shown any aggressive behavior, and that they "do not bother us". The store owners and employees know ex-patients by their names, and say that they go very frequently to talk and buy to their stores. Sometimes they trust things to them but they always pay later.

The concentration of ex-patients in the center of the main city where I did these interviews is stronger than in other neighborhoods where *casas de convivencia* and independently rented houses are. Ayilin's *pensión* in the center of the main city houses several ex-patients and the Pre-Discharge House is there too. Torrey (1997) describes the effects of the concentration of large numbers of mentally ill in New York and New Jersey communities as heavy littering, public urination and defecation, obscene gestures, increased shoplifting, increased prostitution, suicide and threatened of suicide, and lack of physical health care. Regardless the larger number of ex-patients in the center of the city of my study, I did not hear this kind of description in my interviews. Two persons told me about a suicide and about a "patient" urinating in the sidewalk, but they immediately said that they "do not bother" them. They also say that ex-patients living there are non violent and that they have never seen any aggressive behavior. This differs from other studies in the US where the

mentally ill, especially schizophrenics, are described as four or more times more violent than an average person (see bibliographic search by Krieg 2001).

As with the non-mentally ill people living in the *pensiones*, ex-patients are marginals among their middle-class neighbors. Middle class store owners see ex-patients social integration as possible, and they accept them. Ex-patients participate as clients and users of some of the neighborhood resources, but reciprocity is limited because the socio-economical differences among ex-patients and middle-class neighbors in the center of the city are big. They are better accepted than other marginals living in the *pensiones*, but they are seen as incompetent for competitive jobs and in need of protected activities and supervision. These views are not very different from Dear and Tylor (1982) findings in Toronto, Canada, where they say that most people may be tolerant about ex-patients living in their neighborhood but only with qualified supervision. But these views are opposed to the ideals of the professionals of the new programs at the Hospital, who want for ex-patients the least dependence and control possible and their integration as ordinary members of society. They are not ordinary members if they do not have competitive jobs, as middle class people do. As we will see, they can be more “ordinary” members among low-income people in sub-urban neighborhoods, where they share more things in common with other neighbors and where they engage in reciprocal relationships.

### **Social Integration**

For integration into the society, especially in marginal social environments, it is of great importance to have a social network. For people diagnosed with serious mental illness, social interaction is usually seen as a main difficulty because of their lack of motivation, their apathy and shallowness of emotional response, and their inability to maintain productive social relationships, whether caused by the illness itself or the institutionalism syndrome (Wing and Brown 1970). The most important social relationships needed for a successful integration into the community are the ones based on reciprocity. In a reciprocal relationship

there is not one who receives and another who gives, but rather both give, although the exchange may not be equal. The ex-patients from the Clovera reject their position of mere receptors (as supposedly “patients” are in a hospital) and they try to construct reciprocal relationships in which they have socially valued roles.

Of all the ex-patients from the Egidio Clovera who participate in my research, Celeste and Rodrigo are the ones showing the greatest community integration and founding a different identity besides of being hospital psychiatric ex-patients. As I could observe, Rodrigo and Celeste are, for their neighbors and relatives, church followers, hospital employees, and other ex-patients, very valued persons. They are socially valued as people who can give and not only receive; because they have rejected being mere receptors (or receivers of aid) and have constructed reciprocal relationships. They want to actively construct relationships in which they are no dependants, passive receptors of the charity of others. They do not want to be a *carga* (charge, liability) for their relatives. “We don’t want to be a charge for them, but the contrary, we want to help. My son is unemployed now, and if we go to visit him we have to pay for everything because he can’t maintain us” told me Rodrigo once. Wilton (2004) found the same attitude among ex-psychiatric patients in Ontario, Canada. They may accept help but they also want to help others or to reattribute in some way. In this sense, I find that their *externación* from the institution has been, at least partially, accompanied by an abandonment of their “patient” role. They belong to a “psychiatric sphere” but this sphere is not isolated from the “normal” world, it is not a psychiatric ghetto. Celeste and Rodrigo, through their social relations, have created bridges joining their hospital social world and their outside relationships.

Beyond Celeste and Rodrigo accomplishments, I found the conscious intention of not being mere receptors but having reciprocal relationships among all of the ex-patients of my study. Their self-esteem is not as low as to think that they cannot give anything to others. Rather than that, some of them have pretty high self-esteem and are proud of their

achievements. I found the positive work of health professionals to be critical in supporting this attitude, because I have seen them correct ex-patients and telling them that being outside the Hospital is *their* achievement, that *they* did it, etc. Most of them are proud of saying that they have been interned for more than 20 years but they could finally leave the Hospital and that they are doing well. Health professionals from the PSRC and ex-patients share enthusiasm about their experiences. The few cases of failure (marked by the return of some patients to the Hospital) seem to have had little influence.

Ex-patients feel the stigma of being ex- Hospital patients, and their main concern is the difficulty of finding a job. They are expected to work as a key aspect in their recovery. Argentinean society may be sympathetic to the integration of the mentally ill and even to ex-patients living in their own neighborhoods, but people with a mental illness are still seen with fear and ignorance by those who have never been in contact with patients or ex-patients. A high unemployment rate complicates even more the panorama because, as Pedro recognizes, “before giving a job to someone who had been in the Hospital people give it to someone who is not from the Hospital”.

Beyond this difficulty, ex-patients have found new roles such as being coreligionists (“sisters and brothers”) for church members, “good clients” for store owners, friends, girlfriend/boyfriend and wife/husband, and some of them have found roles as workers (in some cases) for employers, babysitters for children, helpful neighbors, and grandparents, sister, son in law, etc. They belong to a “psychiatric sphere” where they find friends, emotional support and crucial social connections for their survival strategies. I do not see this social context as negative but rather supportive for ex-patients. For them, it is not isolated from the outside world but rather interconnected, and it is not a matter of being in or out, but rather in both, at least during the first years of *externación*. They do not stigmatize this integration, and society should not stigmatize it either, accepting not only the ex-patients but also the “psychiatric sphere” that enable him to remain outside the Hospital. From an

inclusionary perspective, ex-patients may be accepted as normal citizens that go frequently and participate of the psychiatric hospital world (or community mental health facilities, in case they would exist), as well as other people participate in other institutions.

### **Social Networks and Survival Strategies**

Most people use their social connections for daily things such as advice, borrowing money or things, child care, getting a job, sharing cable and internet connections, getting a ride, etc. But for people living in deprived socio-economical contexts, to have a social network is crucial for survival. Carol Stack (1974) studying ghetto black families in the United States, and Larisa Lomnitz (1975, 1977) studying marginal people of a shantytown in México, have described their survival strategies as centered basically in social networks. “Marginals occupy the bottom of the social scale in society. They have literally nothing. Their only resources are of a social nature: kinship and friendship ties that generate social solidarity” (Lomnitz 1977: 3). They construct and use social networks defined by Lomnitz as “the flow of reciprocal exchange of goods, services, and economically valuable information” (Lomnitz 1977: 132). People with similar lacks are engaged in cooperation and mutual aid as a way for coping with poverty.

Ex-patients from Egidio Clovera are not without resources (they are privileged among other marginals because the State is in charge of them through the Hospital and income benefits). But they are at the margin of the dominant industrial economy, and they still need help from others because their social and economical security is not always provided. Having a matrix of social links, they know whom to see for each need they have. Because their needs are more than economical, they also rely on social networks for socio-affective needs.

The problem is that they have lost their kin, they do not see family members any more or, if they see them, their relationships are sporadic. Therefore, the typical social network based on kinship is not available for the ex-patients who participated in my research. The solidarity of the extended family does not exist for them. In the context of Buenos Aires

*conurbano* (periphery), where most of the ex-patients come from, it is difficult to compete for resources, and every member in a family has to work. As a Hospital employee told me once,

“the patient suffers his abandonment, but we have to understand it from the perspective of the family situation. A person earns 100 *pesos* and has to maintain a big family; if he puts her sister in the hospital this alleviates his problems. Don’t say abandonment, because he may not have money for visiting her, even for paying the bus to the hospital.”

Because ex-patients do not have a supporting family (*familia continente*), they have to replace this lack with other social links to form a social network. They do it especially with those who have been closer to them for years: other ex-patients. Ex-patients belong to a social group of people with something in common, their experience of hospitalization and their present experience as ex-patients. With one exception, all the ex-patients who participate in my research are involved in close horizontal and reciprocal relationships among them or with other ex-patients and patients. According to Landé (1978) there are two demands for reciprocity: people have to help those who have helped them, and they do not have to injure those who have helped them. Ex-patients also maintain these relationships with patients who are still at the Hospital. María, for example, gives wooden hats to Andrea (who is interned at the PSRC) to sell, and she cleaned the bathroom at the general pavilion when Ester (still at the PSRC in that moment) had an accident and could not work. Then, María spend New Year at the PSRC with the patients.

This situation is similar to Estroff’s (1981) findings among psychiatric clients of a community service, where the mentally ill constructed a social group, and to other studies such as the one done by Wilton (2004) that finds friendship among ex-psychiatric patients. This is different from what happens with ex-patients with mental retardation, according to Edgerton’s (1967) findings. Edgerton states that “to find oneself regarded as a mental retardate is to be burdened by a shattering stigma. Indeed, for the former patient, to be labeled as a mental retardate is the ultimate horror. They reject it with all their will” (1967:205-206).

They cannot accept being a mental retardate and maintain a self esteem. Thus, they try to deny their condition and to “pass” as “normal”; they detach themselves from their past at Clovera and from other ex-patients and cover themselves with a “cloak of competence”, trying to be seen only with “normal” people. Being mentally ill is a stigmatizing label, but it is usually preferred to be ill than to be mentally retarded, because being mentally retarded means that there is something wrong in the intelligence that is not possible to cure. Being mentally ill, instead, may include social causes and possibility of recovery<sup>56</sup>. Some of the ex-patients from Clovera Hospital have a diagnosis of mental retardation, but Clovera is not a hospital for mentally retardate, and they also have other neuropsychiatric diagnoses.

Except for Ayilin<sup>57</sup>, the other ex-patients are engage in a social network and they could expect a cooperative behavior from the patients and ex-patients in that network. Estroff (1981) also observed an exchange system based on reciprocity among psychiatric clients of a community program. The ex-patients participating of my research use their mutual relationships in different ways. For example, one of them may ask another ex-patient to take care of his/her job when for some reason he/she can not attend it, as Ester did with María. One can receive a job from another ex-patient who gives it to him/her. For instance, Rodrigo will give his job at the farm sales post to another person; María gave hats and other things to Andrea to sell, and Pino took Pedro to the Pre-Discharge House so he can sell the workshop

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<sup>56</sup> I did not inquire into ex-patients’ conceptions of their illness, but when they mentioned it they said that is was caused by things such as a “*crisis de nervios*” (nervous crisis), a convulsion, familiar maltreatment, or depression (in a common sense use). According to Sullivan (1994), studies in Hispanic populations show that their use of labels such as “*nervios*” provides explanatory frameworks that reduce stigma and give optimistic views of the future. This interpretation of psychiatric disorders exist, at least in part, among ex-patients of Clovera Hospital, and I could see that it is not discouraged by the professionals of the PSRC, who requires them to be conscious of their symptoms and their need of medication and treatment but do not require to have clear consciousness of their medical diagnosis.

<sup>57</sup> Like the ex-patients studied by Edgerton (1967), Ayilin has been diagnosed with mental retardation, even though her competences are greater than those of some others. She negates her diagnosis of “moderate mental retardation” saying that she has only psychological problems (and her psychologist have also told me that her main problem may be psychosis instead of her mental retardation). But she do not identify herself with psychiatric patients either. Ayilin’s views of the hospital’s patients and the hospital itself are closer to those of outside people who are not in contact with the institution. The way in which Ayilin names the Hospital is closer to the way outsiders name it, with reticence and indirection; she always uses the hospital’s popular and stigmatized name instead of saying “the hospital” as other ex-patients do. She also talks in a suspicious tone about other ex-patients, making explicit gestures for avoiding the use of terms such as “crazy”.

products too. The most common cooperative behavior that I observed is the exchange of information and advice. When they see each other, they talk about a job vacancy where to apply, the office where it is better to ask for a free bus pass, where to buy cheap furniture, etc.

The network of peers also works covering the affective and emotional needs. Six of the ex-patients who participate on my research have girlfriends/boyfriends among other patients or ex-patients, and they have long-time relationships. I often heard health professionals saying that ex-patients who have girlfriends/boyfriends contain each other emotionally. As we saw before, friendship is also common among them. Pino, for example, is considered by Rodrigo “*un tipazo*” (a very good man). They use nick names or abbreviate the names of their friends. They always know everything about each other, which subsidy or pension they have, how much money they have or have saved, where they spend Christmas and New year celebration, the problems each one may have, the accidents, the address, with whom they live, who is boyfriend of whom, the plans each one have, everything, even the more private things. They talked about others with me, even about Ayilin who does not like to talk to them.

Some ex-patients have a less reciprocal relationship with patients, from whom they do not obtain material things but affective ones. Their relationship is one in which they help others who are in worse conditions than them, as an act of solidarity. Mercedes visiting the young woman interned at the Hospital and giving her cloth, or Rodrigo buying cigarettes for the patients interned at his old ward or preparing food and going with other members of his church to give it to a group of patients are some examples. These actions may be seen as charity, but since the ex-patients do not see patients as morally and socially different from themselves, it is better to define them as solidarity, or mutual aid. In a typical charity action, that of beneficence, there is no need of a relationship between the giver and the recipient; there is no affection and nothing in common. It is “a gift of the rich to the poor. . . a business of giving but not receiving, a self-interest obsession of the rich” (Mandler 1990). Charity is

done with people who are not an equal but an “other.” “There is a big difference between evaluating a poor person as someone who can receive charity (. . .) and to feel that community owes something to him” (Gallardo 2000: 14, my translation). According to Gallardo, behind an act of charity there is a social imaginary exclaiming: I’m not like him! Instead, as I see it, the ex-patients engage in acts of solidarity, cooperation, or mutual aid with some patients. We can find the same actions, based on a social relationship and certain affection, between Hospital employees and other people related to the Hospital and ex-patients.

The social networks of ex-patients include also Hospital employees: administrative or maintenance employees, the hair dresser, the theatre director, nurses from their previous wards, employees in charge of productive workshops, etc.(and for some of them also workers of the Integration Council of the city). Ayilin, who does not participate of the ex-patients’ network, makes use of her relationships with employees instead. They belong to the “psychiatric sphere,” but even though they are also in precarious socio-economical conditions, they do not have as many needs and lacks as ex-patients have, and their relationship with them is not reciprocal. Ayilin talks about one of her teachers as her friend, but in their friendship her teacher is always who gives more: she invited Ayilin to spend Christmas with her family, and she always give things to Ayilin, such as a radio and two swimming suits.

Ex-patients obtain from employees especially material things that they can not obtain otherwise. Rodrigo told me that he will ask the hospital’s plumber to install water inside his house, and he buys cheap used things at the store of a Hospital employee. Ayilin always ask nurses for toilet paper, soap, and other products that she is not supposed to have from the Hospital; all the ex-patients have received furniture or domestic items from Hospital employees. Ex-patients and the abilities they have are known at Clovera, and employees, who are closer to them than health professionals, ask them to do odd jobs. According to the ex-patients, Hospital employees and also other people related to the institution hire them for domestic jobs because they want to help them, because they are friends and want to help

them, or because they know them very well, have confidence in them, and know that they clean very well. A nurse from the ward where Celeste used to be interned met Rodrigo one day and asked him whether Celeste can work for her at her house. Celeste told me that the nurse knew that she is very good and willing and wanted to hire her some hours a week. I thought immediately of a possible relationship of exploitation, but when I asked Celeste how much the nurse was paying her it was more than the common pay for such work. A woman who does not have a good salary and who lives in a cheap housing plan would not hire another woman for doing the cleaning and pay her more than what other people pays unless she wants to help her. It is not possible to define these relationships in only one way. Rather, I think that they involve a mix of motivations from the employee's side, such as care (the Hospital function of provision of assistance), altruist solidarity, and also economical interest.

Those ex-patients working for Hospital-employees are engaged in a patron-client vertical dyadic relationship, "an alliance between two persons of unequal status, power or resources each of whom finds useful to have as an ally someone superior or inferior to himself" (Landé 1978: XX). The motivation behind these patron-client relationships is not political (as the ones studied by Landé), it is economical. And it also involves affection and a desire of help the ex-patients giving to them an opportunity to work. María works doing house cleaning at the Hospital hairdresser' house; Celeste , besides working at the nurse's house, washes the clothes of a hospital patient; Sofía has worked taking care of the old mother of a Hospital secretary; and Rodrigo works selling the vegetables of the Hospital farm. The relationships between ex-patients and Hospital employees are ambiguous, and often include affection. Ex-patients try to re-arrange patron-client relationships in a way that reinforce the affective relationship. For instance, when María says "*mi patrona*" (my landlady) she immediately corrects herself saying "*bah, mi amiga*" (my friend).

In a different degree each of them, ex-patients integrate “outsiders” in their social network. Their relationships with them are variable. They have clients that buy them the workshop products because they need them and they are cheap, but they also have clients that buy the products because they want to help them but not giving money for nothing. A woman who lives close to the P-DH, for example, orders weaved coverlets and other things to Pino and the ex-patients at the P-DH instead of buying these things in other place. The store owners and also the Hospital professionals and employees buy Ayilin’s bijouterie not because they really need the bijouterie, and not because they want to clean their consciousness with an act of charity, such as giving a coin to a homeless person. They do it because they want to help Ayilin to live in the community; they now appreciate her. I saw the owner of a *kiosco* greeting her with a kiss and patiently helping her with counting the money. The store owners have accepted Ayilin very well. However, she is not an equal; they just accept to live with people considered different without judging them negatively. Even though she is 42 years old, Ayilin is treated as a little girl, because a retard is her most apparent feature, and she seems to like that. As Edgerton (1967) observed in his research with mentally retardate people, so different from other studies about public attitudes toward people with schizophrenia, “it would almost appear that these incompetent persons have been given a niche (earlier reserved for the “village idiot”) in which they are permitted to live incompetently as long as in the course of this living they do not cause the wrong persons too much trouble. At the very last, normal persons exhibit great sympathy and tolerance for these former patients” (Edgerton 1967: 218). I did not observe how store owners treat other ex-patients with no mental retardation, but from their accounts it seems that they also accept them, even probably with less affection.

In their relationships with “outsiders” in the central neighborhood where Ayilin lives in the main city and also (in less degree) where the *casas de convivencia* are, ex-patients are always in inferior socio-economical conditions than the other person. Regardless Ayilin, I

found from my own experience knowing her that she really wants to have reciprocal relationships. Her lack of monetary resources may be seen as a barrier to that, as Wilton (2004) suggest. She finds difficult to give something in exchange to gifts made to her. But regardless her lack of resources, Ayilin managed to make our relationship reciprocal and a friendship doing things beyond material gifts. She never asked me for things or tried to sell me things; she always tried to protect me, accompanying me to the bus stop when it was dark, advising me to be careful crossing the streets, she encouraging me to save money. I was, as I could notice, the only person who visited her at her room for a long time, and she treated me as a friend. When I gave to her a plant as a gift she immediately looked around and gave to me a decorative candle that she had got from one of her teachers. “You gave me the plant, and I give to you the candle”, she explained. “The person who offers a favor or a gift proclaims her superiority through that act; the other, while returning in equivalent or even greater form the favor or the gift, invalidates the pretension of superiority and at the same time invites the repetition of similar transactions. This constitutes the base of a relationship of reciprocity” (Lomnitz 1975: 28 my translation). Ayilin also tries to find friends among other people, but not ex-patients. She feels affection for some of her health workers or teachers, and she talks about some of them as her friends. She tries to reattribute in some what others do for her, and gives them the crafts she makes at the workshops.

In the more deprived neighborhood, where Rodrigo and Celeste live, I could observe more reciprocal relationships. As I said before, they are the ones who have achieved a larger integration in the community, based not only in their presence, access and use of resources, but also in their social interactions. They started a patron-client- like relationship with “*la señora*” who rents the house to them. She did not know them before, and they were introduced to her through a Hospital employee (Karina, another neighbor). *La señora* rented the house to them very cheap, what was of great help for Celeste and Rodrigo, but also it was a good deal for *la señora* because the house was not in conditions to be rented or, and she

needed the money. Time went through and Rodrigo and Celeste created affection for the four girls of *la señora*, and confidence among them growth. Also, Celeste and Rodrigo improved their income situation and this put them in a more equal position with respect to *la señora* and to Karina, the other neighbor. They started a type of “network of non-kin neighbors” de described by Lomnitz (1977):

Such a network begins with dyadic relationships depending on the degree of *confianza* [confidence, trust] between two partners. The initial favor may be an offer of assistance in an emergency, such as taking care of the children for a neighbor who is taken to the hospital. As *confianza* takes hold, the favors gradually becomes more frequent, until de level of mutual exchange is reached: money, food, use of pots and pans and household items, joint television viewing by both families, and so on(Lomnitz 1977:146)

Celeste and Rodrigo watch TV in Karina’s house and in *la señora*’s house, they spent Christmas together, Rodrigo invited them for his birthday, he and Celeste take care of the girls, sometimes during the night, they cook for them, they take them for walks on Sundays, they prepare a special food for all the kids (the four girls and the three children of Karina) for the Children’s Day, *la señora* lend them her washer machine, and they interact daily helping each other in infinite things. Celeste and Rodrigo even redistribute with them the food supplies they get from the Hospital.

Celeste and Rodrigo have also another group among the people of an evangelic church where they assist. With some members of the church they made friends, and they visit each other. When I told them about the peer-support groups developed in the Unites States, they and also a friend from the church who was present told me that they function like that, everyone is he same, any “brother or sister” is better or in higher position than other. They go every Saturday to the Hospital with Church members. Celeste and Rodrigo are happy giving. They give things, time, and affection to Hospital patients, the children, to church members, to their two dogs, and also to Rodrigo’s family. They do not see their family too much, and their families do not belong to their social network, but they still have a new role as grandparents.

They are valued in the multiple social roles they constructed, and they are integrated into the community and happy.

As Ayilin, they viewed me from the beginning as a friend, and they constructed our friendship pushing also for include my husband in it. I wrote to them a letter when I went to live in the United States; it was a relatively formal letter, but they answered me with affection giving me the title of their friend:

Letter from Rodrigo, June 2004:

*“. . . Erica, you don't know how happy I was for receiving your letter right for the Friends' Day. My 'ball and chain' and I send to you a sticker for the Friend's Day. . . . lots of love for you and your husband. Kisses and hugs.”*

Celeste added in the same letter:

*“Dear Eri, mi other half already told you everything . . . . we send you here a picture of us so your husband can know us. When you come, bring him. I hope for December we can meet him. Lots of love for you both from your for ever friends”*

They constructed a reciprocal relationship with me, giving me as many gifts as I gave to them (probably even more) and inviting me to have lunch and to drink *mate* in their house. Celeste always gave me poems that she writes, and when they said good bye to me in August 2005 they prepared a special lunch and gave to me and my husband a bottle of wine and two packages of *yerba mate* to take to the United States, all wrapped in gift paper. They never considered themselves as inferior but equals.

Ex-patients need to construct reciprocal relationships for improving their self-esteem, having a valued social role, and calming their need of give to others, and not merely receive. I found Celeste and Rodrigo's house location an “enable and socially meaningful niche” (Sullivan 1994), totally different from the “entrapping niches” that are the psychiatric ghettos or institution-like mental health facilities described by the bibliography; a place where everybody needs help from the other, where things are sharing and services and favors are given and received. In that neighborhood at least three low hierarchy Hospital employees live,

and the woman who introduced Celeste and Rodrigo to their landlady is a Hospital employee too. Without being segregated in a facility with staff, they live in the same neighborhoods where the staff lives. Even Hospital workers living there are not directly related to patients treatment or rehabilitation (a gardener of the institution lives there, for example), they are used to interact with hospital psychiatric patients, they do not fear them and they know that they are harmless (the main concern of public negative attitudes according to the bibliography). When I asked Celeste and Rodrigo about their relations with neighbors and how they accept them they did not give any importance to that, and they pointed out the houses of the Hospital employees saying that they know them. It is a place where they can feel accepted without being a sheltered place. We should look beyond the objective material conditions (the dirt street, the lack of water inside the house, more and more) to evaluate how deinstitutionalized patients are doing in the community. A perfectly carpeted and painted apartment with a large TV is not a prove of a better quality of life. As other studies have shown, ex-patients remain inside most of the time, making their social integration more difficult. Rodrigo and Celeste door, instead, is always open, literally.

Studies conducted by the World Health Organization showed that recovery of schizophrenia is better in the developing world than in the industrial world. “the WHO 5-year follow up study revealed that 65% of those who had been diagnosed with schizophrenia in the developing world experienced no or minimal impairment at follow-up, a figure nearly one-third higher than those studied from sites in the developed world”(Sullivan 1994: 8). Sullivan, following other authors, says that most developing societies are “sociocentric”, they place emphasis on social relationships and group cohesiveness in contrast to more individually focused “egocentric” Western societies. In the developed world the first order of business is vocational rehabilitation, while in the non-industrialized societies socially rehabilitation is the primary concern, because only when a person has a social role she is motivated to return to work. There, interdependence is valued, not only independence, and a job does not have to be

a competitive regular productive job. The role of the extended family support in the developing world is also of great importance. In conclusion, developing societies have “enabling niches” for the recovery of the mentally ill (Sullivan 1994).

Argentina is a developing nation but Buenos Aires society has characteristics that make it closer to European and United States models of society than to those of rural India or Colombia. As we saw, the extended family support does not exist for ex-patients. However, looking at the streets of a neighborhood such as that of Celeste and Rodrigo, we can see a big difference compared to most middle-class American neighborhoods. Children playing alone in the street, lots of people riding bicycles, neighbors sharing activities or work or talking at the doors, small stores for the every day purchase of bread, milk or meat where people talk to each other while waiting to be attended, and a bus stop with several persons always waiting. It is like the neighborhood where I grew up, every one knowing about other’s life, with lots of gossip, but also mutual help.

I am not saying that a more urban location may not allow recovery, but it seems that when the neighborhood is closer to the centre of the city, there is a lesser degree of social interaction. Even though there are a larger existence of communitarian resources (cinema, theater, museums, restaurants, coffee shops, parks, etc), most of them are commoditized and therefore not easily accessible for ex-patients. According to Patricia, a psychiatrist from the Pre-Discharge House, ex-patients at *casas de convivencia* (urban but not inner city middle class neighborhoods), have a higher social interaction in their neighborhoods than ex-patients living in *pensiones*’s rooms in the centre of the city. In the city, ex-patients do not have money to use the resources available, and as I could observe with Ayilin, she uses the stores of her neighborhood for socializing, something that is also possible to do in less central and in suburban neighborhoods that are full of stores too.

These findings differ from Dear and Tylor (1982) findings about the rejection against the mentally ill living in the community in Canada as stronger in “stable, low-density

residential areas with many young children” (167). Segal and Aviram also found that in the United States, where “the majority (66%) of complains received by facilities are made against those in suburban areas. . . the suburban area, which is often held as an ideal resource for the sheltered-care facility, may in fact be quite problematic . . .” (1978:112). However, it is problematic to compare the findings in other countries with the situation in Argentina, because the urban and suburban settlements are different in both countries.

Regarding the normality of the live of ex-patients living in the community, I find Celeste and Rodrigo’s lives as a sort of paradigm of recovery. They have a house independently from the Hospital but the rent is cheap enough to allow them to have extra money for other purchases. They are not substantially different from the people living in their neighborhood. I see their life there as a “normal” life. Those who analyzed and criticized process of deinstitutionalization have noticed that there is always a homogeneous ideal of “community” where patients have to be discharged. Not enough consideration is given to communities different from white Anglo-Saxon middle-class ones (Johnson 1998). As Johnson says, there are differences among people and not everyone fits in the same type of community. Ex-patients living in *casas de convivencia* in relatively low middle class neighborhoods may not fit there as equals, but they are not rejected and isolated inside their houses. They are present and use the neighborhood resources as other people do. They are in a special situation because they do not have an independently maintained house and the Hospital pays for that, but this situation allows them to use the money they receive or earn for other things, and they are not as different from other people in this way. Ex-patients that live in a *pensión* room in the center of the city, as I observed from the case of Ayilin, are those whose social integration as valued persons is more difficult. It is not common for poor people to live there, but they rather live in suburban neighborhoods, and the population of cheap *pensiones* is not the common middle class population of the city. Therefore, not only the monetary capacity but also the external aspect of ex-patients differs from most people living

in the city. The situation makes people confound them with *vagabundos* (vagabonds, homeless) or other stigmatized populations). Ex-patients live there independently and it means that they have to pay for their rooms in a *pensión*, and this led them without money to spend in the multiple resources available in the center of the city. That is why Ayilin, different from Celeste, complains so much about not having money to buy the things she see at the central stores. It would be nice if ex-Hospital patients, as well as other marginal people, can re integrate into the society living as the more privileged middles class members do. But it would need to be more than a carefully planned policy of deinstitutionalization; it would require a radical socio-economical change.

## Chapter 6

### Overview of the Problems of Deinstitutionalization and Some Observations From the Experience in Argentina

Argentina has many differences with respect to other countries where deinstitutionalization has been dominating mental health policies for forty years. Deinstitutionalization as a policy, as it is mostly understood, implies the abandonment of the psychiatric hospital as the main system of mental health care and the adoption of a community-based system. In Argentina, with a few exceptions, no community-based mental health system has been developed, and the psychiatric hospital remains the norm in most of the country. Buenos Aires Province, with 13,827,203 inhabitants, has more than 38 percent of the total country population (36,260,130 inhabitants)<sup>58</sup>, half of the psychiatric “beds” for internment, and three of the six biggest public psychiatric and neuropsychiatric hospitals of the country<sup>59</sup>. Its neuropsychiatric public hospitals are in precarious conditions, with lack of personnel and professionals, with deteriorated buildings, with low budget and with few expectations for developing progressive and innovative programs. The health professionals of Egidio Clovera running the *externación* programs that I have described, and the ex-patients experiencing it, are just a small group. I did not describe a massive de-hospitalization or a new long-term care policy.

Regardless these main differences between the experiences I described in Argentina and the researches of experiences done in other countries where deinstitutionalization has been around for several years, I think that it is helpful for the planning of a future mental health policy to look at the achievements and also at the numerous problems brought to these other places by the way in which deinstitutionalization was made. Looking from the

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<sup>58</sup> Census 2001 INDEC: <http://www.indec.mecon.gov.ar>, consulted April 25, 2006

<sup>59</sup> National Health Ministry according to year 2000: <http://www.deis.gov.ar/guia.htm>, consulted April 15, 2006

knowledge of other foreign experiences at the *externación* programs and the life's experiences of the ex-Clovera Hospital patients, we can learn to value their particularities, proceedings, and achievements as well as to know their possible deficiencies; and this may permit to know what to avoid and what to improve in future policies.

In general, there have been no questionings about the need of a radical transformation of the mental health system everywhere. Most researchers and health professionals agree with the ideals of “deinstitutionalization” as the way of doing this transformation, minimizing “the amount of care provided in institutional settings, particularly in the state mental hospital, and to increase the amount of care provided by outpatients agencies in the community” (Bacharach 1989:161). Studies show that the subjective quality of life of many ex-patients deinstitutionalized from hospitals has improved, since ex-patients prefer to live in the community than in the hospital. In the community they have at least some privacy and freedom for choosing when and how to do the simple things of life. Ex-patients in different places have improved their family relationships, their domestic skills, and also their sociability. In addition, the community-mental health centers and mental treatment in general hospitals provide a diversified set of services to a wider out-patient population, and services such as counseling, advocacy, and psychological treatment are now available for people with social and emotional and addictive problems who did not receive mental health treatment before. Mental health services, instead of being locked in psychiatric specialist hospitals, are now more accessible and integrated to general health services. [Anthony 1993, Sullivan 1994, Botega 2002, D'Avanzo et al 2003, Kilpatrick 1996; McCourt (1993); Davison et al (1995); Brown (1985); Shadish et al (1989);]. Each of the countries where deinstitutionalization has been implemented, however, vary in its accomplishments. While the United States, the first country starting the process, seems to show more failures than successes, Italy is usually named as the country with the most revolutionary transformations (Scheper-Hughes and Lovell

1985). There, the ideals of Franco Besaglia and colleagues, through the “democratic psychiatry” movement, the Law 180 and other later legislations<sup>60</sup>, eliminated completely the *manicomio* (asylum, psychiatric hospital). Most importantly, the way of thinking about mental illness was transformed from medical terms to socio-political ones, and this ideas were spreader to different sectors of society (unions, politicians, general public) (Scheper-Hughes and Lovell 1985; Döring 1985).

### **Overview of the Problems of Deinstitutionalization**

In spite of these accomplishments of movements and policies of deinstitutionalization everywhere, many problems have grown because of to actual implementation of laws and the actual practices and understandings of what deinstitutionalization, community-based mental health facilities, and mental illness itself is. The experience of deinstitutionalization in the Unites States since the 1960’s suggests, as Gerald Grob shows, that even though some important achievements were reached, the deinstitutionalization programs suffered of “rhetorical claims” and “unrealistic expectations” (Grob 1994). The most common problems that appear in the bibliography are hospital rushed downsizing and inefficient or even inexistent planning and budget for adequate community residences and facilities for community treatment. As a consequence, visible problems have raised, such as abandonment, homelessness, unemployment, lack of treatment, symptom relapse, re-hospitalization,

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<sup>60</sup> “Democratic Psychiatry” is the formal organization into witch Italy’s anti-institutional psychiatrist and mental health workers would converge in 1973. Anti-institutional Law 180, issued in 1978, is the end of Franco Besaglia itinerary towards Italy’s mental health reform. The law 180 “put a freeze to new admissions to psychiatric asylums and demanded that all current and chronic patients be gradually discharged and reintegrated into community life through a network of outpatient services. Meanwhile, existent psychiatric hospitals were to be unlocked and patients’ civil liberties returned to them. The law prohibited the construction of new psychiatric hospitals or the upgrading of all existing ones. New patients were to be evaluated and treated in the community. If necessary, during an acute phase of illness or distress, a person could be admitted to psychiatric wards of general, district hospitals. These wards could not contain more than fifteen beds, and in no case could compulsory hospitalization last for more than fifteen days, with independent judicial reviews required at the second and seventh days after admission” (Scheper-Hughes and Lovell1987:35) In 1994 a new law obligated psychiatric hospitals to close down, and several laws specified the ways in which hospitals have to accomplish that. Between 1995 and 2000 the 67 psychiatric hospitals still opened in 1994 closed. Legally, some of the buildings of psychiatric hospitals may be used as residential facilities for the elderly and mentally retarded, but not for psychiatric cases, and they must to be run by social services. Nonetheless, few psychiatric facilities are still functioning in some psychiatric hospitals while waiting for their accommodation in the community (D’Avanzo 2003)

criminality, and even incarceration, especially appreciable in the United States (Scheper-Hughes and Lovell 1985; Flory and Friedrich 1999; Botega 2002; Bachrach 1983; Shadish et al 1989; Krieg 2001; Torrey 1997; Hombs 1990; Grrrenblatt 1992; Grob 1994; Hopper 2003, among others). This critical panorama affect not only former hospital patients but also persons who have never been institutionalized but have been carrying severe emotional distress for many years without receiving treatment or receiving only medication. The media have had an important place in enlarging the magnitude of the phenomenon and influencing negatively public attitudes. Citizens have reacted with indifference or, again especially in the United States, with strong hostility to mental health facilities opened in their neighborhoods, forcing the formation of “psychiatric ghettos” (Segal and Aviram 1978; Brown 1985). Those who are against the closure of psychiatric hospitals say that the abandonment of former patients done by deinstitutionalization has led to the situation in which many psychiatric former patients are now in jails and prisons. “In New York, the estimated population of 10,000 mentally ill inmates in the state’s prisons now surpasses that of the state’s psychiatric hospitals” says Torrey (1997) basing his information in newspapers’ publications.

The violent behavior of the homeless mentally ill, well covered and published by the media and also by official organizations (NAMI<sup>61</sup>) stating that mental illness is biologically based, made some people talk about the need of enforce medication and also re-institutionalization (Torrey 1997). Others, instead, call the attention to the socio-economical marginality and oppressive institutional contexts as factors creating the violent behavior, and they find the solution treating the society and not the vulnerable individuals (Szasz 2004; Scheper-Hughes and Lovell 1985).

The homelessness problem is the most visible and alarming negative consequences of deinstitutionalization, and probably the most named by the critics of deinstitutionalization. In

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<sup>61</sup> National Alliance for the Mentally Ill (NAMI) is an advocacy and support group composed mostly by family members of persons diagnosed with schizophrenia and bipolar (maniac-depress) illness. They support the biological theory of serious mental illness, and have enormous influence in the National Institute of mental Health (NIMH).

Argentina, where the deinstitutionalization process is just by start, we have no serious notice about mentally ill homeless and episodes of violence. From the purposes of my study, however, these “foreign” problems are important in the way that they make professionals in the Hospital aware and sensitive to what may happen with a bad implemented mental health reform. This awareness plays a role in the existent discussion about the role of the psychiatric hospital. The old asylum (*manicomio*) has been questioned in Argentina as well as in other countries, but there are contradictory ideas about it. The ghost of abandonment (especially images of homeless mentally ill from the United States) plays a role in the defense of the psychiatric hospital as the protective arm of the State for the poor, even among those who criticize it. At the Clovera, professionals such as Alicia, psychiatrist from the PSRC, want to transform the *manicomial* system, but from within and step by step, watching out for avoiding any intent of backward movement of the State in its role as public health guarantor. Alicia thinks that there should be a more integrated health system where mental health is not separated from the general services, and with options of staffed housing even for the more disable patients. But in regard to the psychiatric hospital she says that its presence is needed for short internments when families cannot attend patients and when separating them from a problematic context is positive. “One of the functions of the psychiatric hospital is to provide asylum for the person experiencing severe difficulties in living with himself and others,” says Esroff in the same sense (1981:254).

Other health professionals, as we saw in the case of Micaela, psychiatrist from a chronic ward, rely more in the better results of the Italian mental health reform, and have more confidence in the idea of closing the psychiatric hospitals. Studies evaluating the closure of psychiatric hospitals and doing a following up of discharged patients in Finland, Australia, Canada, and Italy show that “the risk of abandonment that deinstitutionalization suggested was not observed” (D’Avanzo et al 2003:33) At the Egidio Clovera, Micaela and others are

opposed to the programs (Psychosocial Rehabilitation Center, Pre-Discharge House, Day Hospital) for being used as a kind of escape valves and not really transforming the system.

Besides the homelessness problem, I am more interested here in other less visible problems related to the way in which deinstitutionalization has been applied in the United States and also in other countries, such as the United Kingdom, Australia, Canada, South Africa, or Italy. Knowing these problems allow to evaluate or understand achievements and failure in the first steps done towards deinstitutionalization in Argentina, and to identify its particularities.

The literature, especially studies done by sociologists and anthropologists, criticizes the process of deinstitutionalization as being not really deinstitutionalizing. Sometimes patients from psychiatric hospitals are just transferred to other institutions because of a lack of small community facilities or a lack of believe in patients' ability to manage in the community, and therefore the process should be called "trans-institutionalization", with no real changes in the way patients live. Other times, community-based small facilities exist, but the life is there planned and organized *for* the ex-patients and not *by* them, and without any change in how they are viewed. The institution remains inside them, and therefore some authors talk about de-hospitalization instead of de-institutionalization. In the same way, even when ex-patients have adequate community facilities and a staff that intensively work on changing their powerless identity, external forces such as social security benefits and income programs come to pull down this work requiring ex-patients to remain disabled, impaired, and powerless for being in the programs.

### **Trans-Institutionalization**

The less visible problems of deinstitutionalization are not centered on the effects it has had in the community but on the effects it has had on the ex-patients discharged from hospitals and in its subjective experience. Even considering that the majority of ex-hospital patients are happier in their new accommodations, these accommodations are far from the

ideal community facilities, and ex-patients do not show fundamental differences in how they are treated. “Trans-institutionalization” refers to a failure in adopting a community-based new psychiatric system after closing or downsizing institutions. In states and cities where the process of deinstitutionalization was made more carefully, probably “the risk of abandonment that deinstitutionalization suggested was not observed” (D’Avanzo 2003), as this author found in her study in Italy. But, as the same author recognizes, “the psychiatric hospitals seems to have been replaced only partly by community residential facilities” (2003: 33). In the United States most ex-psychiatric hospital patients have been moved to other institutional settings such as nursing homes or boarding care homes instead of small half-way houses, group homes, or independent housing programs. “Care for the chronically mentally ill is provided largely in institutional settings, and in ones that are not at all the kind of progressive community care settings first envisioned” states Shadish and colleagues (1989:11). These authors also say that the vast majority of “chronic patients” in the United States reside either in nursing homes or in board-and- care homes “characterized by poverty, stigma, social isolation, and poor care”(Shadish1989:3).

Brown(1985) describes nursing homes, boarding homes and single-room occupancy hostels as “the new custodial private sector;” mini-institutions where patients have been transferred from asylums and where they do not find any change in the dehumanizing elements of the asylum life; unhealthy and oppressive environments where fraud, theft, heavy drugging and deliberated poor care, and where physicians and registered nurses are a rarity and where there is no following up on medication and psychological treatment. These facilities, denunciated Brown, are supported by federal reimbursements that pay for treatment

in the most custodial locations rather in the more innovative care settings. . . Many small facilities of 15 beds or less are the facto ineligible since federal regulations requires too much medical orientation, staffing, and equipment for such places to possibly meet their requirements. . these contradictions led to Medicaid supporting nursing homes rather than more beneficial placements such as halfway houses or group apartments(Brown 1985:101)

Brown describes in detail other Social Security Income and Medicare and Medicaid regulations that work against halfway houses or group homes, which would be better facilities according to the original intentions of mental health policymakers.

The rise of nursing and boarding homes in the United States was caused, mainly, by a transfer from state funding of care in psychiatric hospitals to federal funding (especially through Medicaid) of third party (privates) community-based facilities. In 1962, before Aid to the Disabled (1963) and Medicaid (1965) were created and the deinstitutionalization movement begun, the federal dollars for psychiatric treatment were of 2%, but in 1994 it had increased to 64% (Torrey 1997:99). According to several authors, the process of deinstitutionalization was speeded in a messy way, consisted on “dumpling” patients thanks to the new federal dollars available for patients cared outside state hospitals. “Because of the incentives created by federal programs, hundred of thousands of patients who have been technically *deinstitutionalized* by being discharged from state psychiatric hospitals have in reality merely been *transinstitutionalized* to nursing homes and other similar institutions where federal funds pay most of the costs” (Torrey 1997:102). From 558,239 inpatients in state psychiatric hospitals in 1955, the year 1994 saw just 71,619. The magnitude of this reduction is better appreciated considering that the size of the U.S. population in 1955 was 164 million and in 1994 260 million (Torrey 1997:8). In Louisiana, for example, patients in public mental hospital went from 8,271 in 1955 to 1,091 in 1994; and in New York from 96,664 to 11,286 (Torrey 1997:206).

The industry of these private institutions has been reinforced, as Brown (1985) recognizes, by “their status as private enterprises (that) gives them a certain acceptability and leeway in a society which is ultimately geared to free enterprise more than to human service”(page 108). But the rehabilitative intentions of these new for-profit institutions have seriously been questioned (Shadish 1989). The consumerist image of a system of care as a supermarket in which ‘clients’ shop for their health needs, well accepted in the United States

culture, has been criticized by Swartz and MacGregor (2002) from the perspective of the deprived socioeconomic conditions of the vast majority of mentally ill South Africans, who are no participant consumers and can not choose the most convenient for them but instead have programs imposed to them. Probably this is the same reality for many poor North American mentally ill.

The potential problem of “trans-institutionalization” exists in Argentina as the fear of a possible growth of private psychiatric hospitals if the public ones close. Also, after a decade (1990’s) of neoliberal policies that meant the privatization of most of the companies and services owned by the state, some professionals and also people from political movements say that the “*desmanicomialization*” (deinstitutionalization) hide the possibility of privatization of mental health care, and not a real transformation of the system. The ghost of privatization rises as a threat when state hospitals closure is mentioned, because of the common ideas about the role of the state as the natural guarantor and responsible for its citizens. These ideas are not necessarily opposed to a community-based system of mental health care, if the State is the direct responsible for that. But the lack of financing planning for that and the fear of a public abandonment of the mentally ill to the hands of the free market, together with the fear of a lost of jobs positions for hospital employees, has led to the a defense of the psychiatric hospitals by many political organizations<sup>62</sup>.

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<sup>62</sup> Sergio Villamil writes in “*Prensa Obrera*” (676 - 3/08/2000: <http://www.po.org.ar/po/po676/leyde2.htm>, consulted May 29, 2006) a critique of a new legislation in mental health in Buenos Aires City. He says that luckily, the neuropsychiatric hospitals exist for the treatment of thousands of forsakes patients, and that closing them is not a progressive idea because it implies the privatization of the mental health. In the article “*No al cierre del Moyano*” (*Tribuna de Salud* 2005, 4 (10): <http://tribunadesalud.com.ar/taxonomy/term/6?PHPSESSID=2187013e10ee5ace60bdb13347c5e7a4>, consulted May 20, 2006), the redaction committee describe the new mental health law of Buenos Aires City (ruled in 2005), as part of a policy of liquidation of the public mental health system and its privatization. They state that the underlying intentions are a business that the government wants to do selling the grounds of the hospitals (located in s strategic zone in the core of the city) and opening a business for the private sector as runners of the future community-based system. The interests of the Hospital employees are, of course, behind this defense of the Psychiatric Hospital.

### **Deinstitutionalization at a Subjective Level: Just a De-Hospitalization Process**

When patients are discharged to community half-way houses, group homes, or other community based facilities instead of to other institutions, it does not necessarily mean that they are experiencing a real deinstitutionalization. Mental health consumers in the United States recognize that even outside the mental hospital the situation of powerlessness and lack of self-esteem continues, because the “role of patient” has not been left with the hospital. “You can leave the hospital, but you still have the institution inside,” told me David, an activist for the rights of mental-health consumers. According to Daniel Fisher, director of the National Empowerment Center, the main problem in this regard is that people do not believe in the possibility of recovery from mental illness, they see this condition as permanent<sup>63</sup>. The anthropologist Kelly Johnson (1998) in her book about the deinstitutionalization of women from a mental hospital in Australia, also says that deinstitutionalization “did not fundamentally change the way in which the women’s subjectivity was constituted or managed around them” (1998: 146), the idea that the women were disable was not questioned at all during the process of hospital closure. Leslie Swatz and Hayley MacGregor, analyzing the South Africa stage of deinstitutionalization (yet in its beginnings), also refers to a “plan of management” of the mental health policies that does not take into account patients subjectivity or individuality. In a administrative routinization of care “the concerns of the patients are subordinated to a plan of management in which there is little space for individuality” (Swatz and MacGregor 2002:166). In England, Cristine McCourt Perring’s ethnography of a psychiatric hospital closure (1993) also shows this lack of attention to patients’ subjectivity and individuality by those in charged of the group homes where ex-patients went to live (non highly trained or professional staff). Patients were infantilized, considered not fully social or mature, and dependant and needed of paternalistic supervision,

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<sup>63</sup> “An Empowerment Model of Recovery from Severe Mental Illness: An Expert Interview with Daniel B. Fisher, Md, PhD.” *Medscape Psychiatry & Mental Health* 19 (1) January 20, 2005  
[http://www.power2u.org/Expert\\_Interview.htm](http://www.power2u.org/Expert_Interview.htm), consulted April 26 2006

and their needs were not seen from their own perspective but from staff's perspective of what is good or bad for them. For example, a woman who had a unhappy past as a wife was placed in a mixed group home with the idea that it would be good for her to cook and clean for men, but the staff did not take into account that she did not want to be put back in that position. Another example is the requirement for ex-patients to participate in workshops and daily activities without consideration of their age and right to retirement. In a normal life, most old people stay at home most of the time.

Deinstitutionalization should imply not only a transfer from hospital care to community care, but also ex-patients acquisition of self-esteem, empowerment, and a new socially valued role linked to the lost of their stigmatized "patient" role. This process requires that the people surrounding those labeled as mentally ill recognize them as socially valued citizens. Anthropologist like Cristine McCourt Perring (1993), Nancy Scheper-Hughes (1985); Kelly Johnson 1998, or Sue Estroff (1981) make critics to the deinstitutionalization process in different places from that perspective. As Estroff recognizes,

de-institutionalization has, for the most part, been simplistically effected through movement away from the architectural embrace of hospitals. But institutions, of course, are complex, extending beyond walls to the articulation of traditions and values at a societal level. In this sense, the institutions of chronic mental illness have been little affected by the escape from institutional buildings. The roles, expectations, stereotypes, and responses that accompany being a back-ward patient or a long-term community out patient have changed little. It is as if we thought what was noxious to patients was something present in the actual walls of hospitals (Estroff 1981:253-254).

Cristine Mac Court Perring (1993) describes deinstitutionalization in England as it was done in thee hospitals that closed. She demonstrates that deinstitutionalization does not finish with the placement of ex-hospital patients in the community. As she shows in her book, health authorities and local authorities made an organized and well planed program of deinstitutionalization, and there were no important financing problems. Many ex-patients went to live in real community- based facilities: group family-like homes managed by voluntary organizations. Four or five residents lived there with different degrees of staff

supervision according to their level of dependency. However, what McCourt Perring's description and analysis of the group homes shows is that even these carefully planned community housing programs, with good material conditions, good location, and activities and health services ready for the residents, keep many of the characteristics of institutions, and that instead of being deinstitutionalized, ex-patients were just de-hospitalized. Staff encouraged ex-patients to take choices and be more independent but only inside the house, in the domestic skills and routines of the home. Besides the home routine, ex-patients were considered not able to decide and take choices about their jobs or activities and had to follow a structured program of sheltered work or social activities only within a "psychiatric sphere" of day centers and other mental health community facilities. The group homes regimes and the activities encouraged do not enable ex-patients to change their patient identity and find socially valued roles in the community. Ideally, group homes have a paternalistic model of an ideal-type family, and not of an hierarchical institution. But in this family-type model residents did not interact in a reciprocal way with staff; they do it as dependants. The group homes, according to McCourt Perring, perpetuated dependency and institutionalism. "The long stay patients are leaving, but they are not fully discharged from their patient role," states McCourt Perring (1993:105). The author says that to remove institutionalism "we need to consider the way the former patients view themselves in terms of the continuing or changing power relations in the institution or the world outside" (1993:16). Instead, and "like the asylum, the psychiatric community centered on the group homes retains a stigmatized identity. . . the group homes residents found themselves isolated within the community (1993:23). The walls of institutions were replaced by those of group home staff and a community psychiatric sphere.

For my research in Argentina, the previous observations are important for a comparative analysis of ex-patient's life in the community. None of them live in a staffed home, and they have much more freedom for organizing their lives, what at the same time

means that they have to confront more challenges and less daily support. I found that the non staffed facilities allowed the ex-patients to develop activities of their own interest and ways of managing the house in their own manner, without staff saying them what to do. Not all persons have the same abilities, and solidarity and complementation is encouraged. For example, Celeste does not know very well how to cook, and does not move with confidence in the public transportation system to go far from her house (which is very close to Clovera Hospital), but Rodrigo, is partner, does these things very well. At *casas de convivencia* domestic tasks are divided, depending of each one preferences or abilities, and therefore usually one cooks, other cleans, or another goes shopping.

The present possibilities to deinstitutionalize psychiatric patients from Egidio Clovera Hospital, offered by the programs Psychosocial Rehabilitation Center, Day Hospital, and the Pre-Discharge House and *casas de convivencia*, are centered on patients medically stable and with a self-help (*autovalimiento*) that allows them to live alone. Staffed housing programs such as a half-way-house or group homes are not available, and therefore patients with high dependency are not *externados*. Clovera Hospital does not have any program for the *externación* of patients in need of permanent care, because only a policy of hospital closure would require that. The programs focus only on people from whom everybody at the Hospital say that “they should not be here” (implying that the other more dependant and less ‘lucid’ people should be there). The limitations of the community facilities available, however, may be seen from a side that is positive for ex-patients. First, some patients who may be transferred to staffed facilities if they would exist, are presently pushed to reach an independent life alone or with peers in a *casa de convivencia*. Some of them, as Celeste, would probably not be able to leave the Hospital alone, but she did it surprisely well with Rodrigo. If staffed and more secure and less risky options for living in the community would exist, professionals would may be tempted to transfer patients such as Ayilin or others with mental retardation to more institution-like staffed facilities in the community. Instead, Ayilin

and others have been pushed (with her willing) to the situation of having to arrange by themselves in the outside world, and this experience shows that they find strategies for survival and that they get into social relationships that surprise their doctors. Of course, what I have to emphasize here is that those ex-patients are not really alone, they just live alone. They have psychological and psychiatric treatment, and they have a place where to refer for advice or any need they have. That place is the PSRC, the Day Hospital or the Pre-Discharge House. These structures belong to the Hospital, and they exist because of the Hospital. Having those places as reference keeps, in some way, the dependence on the Hospital, but I see it as a relatively positive dependence, as a support.

Living without staff allows the ex-patients to organize their days as they want, and to have more freedom for doing the domestic work in the way they want. They are responsible for managing their medication, being on time at work, class or other activities, cleaning the house, washing their cloth, buying the staff needed, etc. without any person treating them as incapable and telling them what to do or doing things for them. Mercedes, instead, stays a lot of time in the *casa de convivencia* where she lives and nobody would think that this is pathological, because she is old and everybody recognizes her as “*la abuela*.”

Living alone, ex-patients escape from the problem of home-staff undermining a real deinstitutionalization by maintaining the same stigmatized view and hospital-like management toward them. But as Johnson (1998) has shown, this unchanged view can also be maintained by professionals from the hospital and from family. In an ethnographic study of women being deinstitutionalized from a mental hospital in Australia, Kelly Johnson (1998) shows the maintenance of the stigmatized identity by ex-patients families and hospital's health professionals in charge of their rehabilitation, discharge and re location in the community. It is not the case, again, of the ex-patients who participated in my research and their hospital health professionals and family. Their families are not present nor influencing in their *externación*, health professionals encourage them to construct a new identity, not

working as if “the walls of institutions were replaced by the walls of professionals,” (Johnson 1998:159) but trying to break this walls.

Professionals from the Psychosocial Rehabilitation Center of Clovera, as I could observe, have a different perspective. They insist telling the ex-patients that they are not patients from the Center any more, that they are ambulatory patients as any other people, and that they need to detach themselves from the Hospital. They believe in their recovery, they are convinced that they can find the way of having a “normal” life. Their psychiatrist and psychologist from the PSRC and the P-DH believe in them and gave them the opportunity to prove themselves and others that they could manage well alone or with peers in the community.

### **Social Security**

The process of leaving a patienthood identity finds other obstacles, according to the bibliography, this time not in people (family, home staff, hospital professionals) but in government income maintenance programs. Sue Estroff (1981) did an ethnography of the lives of patients (“clients”) participating in PACT, a psychiatric program intended as an alternative to institutionalization and part of a broad range and innovative community mental health services of Madison, Wisconsin, during the late 1970’s. There, and different from the previous examples but more close to what I observed at the PSRC in Clovera, staff and mental health professionals did everything they could to allow the clients to find a new valued social identity. Nevertheless, Estroff’s description shows the same maintenance of a low self-image and stigmatized identity in the PACT clients. Health professionals at the program encouraged patients to get jobs and a social life outside the psychiatric sphere, but the income maintenance programs available for “disable” people discouraged them to see themselves in a different way, and put them together with mentally retarded and physically handicapped people. Clients used these benefits (Supplemental Security Income (SSI), Social Security Disability Income, veteran’s benefits and local Welfare) as a way of maintaining themselves

in the community and being eligible for psychotherapy and other health care services. SSI<sup>64</sup> perpetuated their “crazy life” by making being “crazy” an attractive and safe source of income compared to the bad and difficult to keep employment opportunities in the competitive world. Applying for SSI implies that clients formally recognize their inability to work. “In looking at *why* these persons get pay, it becomes evident that their *disabilities* function as do others’ *abilities*, that their *incompetence* reaps for them what others’ *competence* earns” (Estroff 1981:119). The walls of institutions were replaced here by those of the benefit programs. The system available and used by clients to survive in the community is “a system in which their identities or roles as crazy people are the means by which they ‘make it’ or survive” (Estroff 1981:38). Clients at PACT were involved in a process of constructing, reconstructing, and elaborating a psychosocial and handicapped identity.

The ex-patients from the Hospital where I did my research, as well as the clients in Estroff’s study, thank the possibility of receiving some money from governmental benefits. Part of their survival strategies also consist in search for pensions, subsidies, social plans, free bus passes, etc. And most of these programs require them to be disabled. However, I do not think that their main occupation is being a “full time crazy” as Estroff observes in the population she has studied. It can be explained in part by the kind of social security programs that we have in Argentina and the flexibility of its control, and in part by the socio-economical context in which some ex-patients live, what makes them no so different from other population who lives in the same conditions even not being mentally ill. The ex-patients, as those from Estroff’s research, are worry about money, about jobs. “You working?” or “Got a job?” is the way they greeted themselves in Estroff’s account, and also

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<sup>64</sup> SSI was created by congress in 1972 and was implemented in 1974 as a benefit program for aged, blind, and disable persons who has little or no other income and who need help in maintaining basic needs. To receive SSI for disability a person has to have a physical or mental impairment that unable him/her to engage in substantial gainful activity, and must be medically determined and have a duration of at least 12 month. (Estroff 1981:150) Presently, consumer advocates are working with governments in alternatives such as being allowed to work while being in SSI.

is the main topic of conversation among the ex-patients of my research. Subsidies, pensions, or “plans” are also part of the conversation.

They look for a secure and safe way of making a living, and some income maintenance governmental programs allow them to have this safety. But the few available subsidies in Argentina do not really require ex-patients to “make it crazy”. The “mentally ill *externación* law” in Buenos Aires Province does not talk about disability or incapability, it only recognizes that when a psychiatric patient is *externado* from a hospital he may not have anything (job, family, resources) and he will need monetary help for a while. The subsidy is given to ex-patients who have not family or whose family has no resources to sustain them, until they find a job and can sustain themselves. It is renewable each six month. An ex-patient applying for this subsidy does not have to recognize himself as disable, but just a person who, as a prisoner who have left jail after a long time, will have problems in re-organized his life. Another very recent subsidy, that of “back to home” program, also is understood as a way of leaving the hospital in a context in which unemployment and marginalization is the reality for many people, and would be ex-patients reality too, especially incremented after a long separation from the outside world.

Things are different with other income maintenance program: The “National assistance Pension” (Law 18.910), the benefit most desirable by ex-patients because of its perpetual characteristics that gives them a feeling of security, is the most similar program to what SSI is in the United States. It is an amount of money given by the State because of permanent or prolonged disability. It is difficult to obtain, and a 76% of diminution in the labor capacity because of any class of incapability is required. The difference I found between ex-patients from the Clovera and the clients studied by Estroff in the U.S., is that the ex-patients do not really believe that they have a 76% incapability for work, and neither their health professionals believe that. The pension, as well as the other subsidies, is not enough money to make a basic living just from that, and they only consider it as a legitimate help

because of the socio-economical adverse conditions of the Argentinean context, and not because of their illness itself. Ex-patients are not required to constantly prove their condition (of disability in their case) once they get the pension. It is for life, and nobody will control or supervise that they are not working or that they are not disable any more. Their difficulties to get jobs are related to the context of generalized unemployment and large competition for jobs, and to social ignorance and therefore discrimination to people labeled as mentally ill. These difficulties are not related to ex-patients illness itself. I agree with Estroff (1981) in thinking that we do not have to traspass a socio-economical problem tone of individual health. A person who does not work shows not a symptom of his illness but a symptom of the kind of society and system in which he is involved (Estroff 1981:168).

Mental health professionals who sign the incapability certification and governmental employees who assign the national pensions take into account other things rather than ex-patients actual incapability. They rely more on the other requirements for the pension: to have nothing, to be completely vulnerable, to not have any other kind of retirement or subsidies for itself or for a spouse or common-law partner; to not have any kind of resources, goods, or income, and to not have any relatives legally obligated to support them. Merchant (2000), director of another psychiatric Hospital in Buenos Aires Province, talks in his book about the ghost of marginality and helplessness as a destiny for *externados* long-term psychiatric patients, because of the lack of familiar bonds and economical resources and scarce job opportunities in the present difficulties of the labor field. As he recognizes, Argentina is immerse in problems of unemployment, sub-employment, precarious and transitory jobs. The very competitive nature of the few jobs available are undermined for ex-patients because of their advances age, lack of specific formation (education), and other exigencies. The unemployment rate have improved from 21, 5 percent in May 2002, to 14, 5

at the end of 2003, and to 11, 1 percent by the middle of 2005, when I started my research<sup>65</sup>. However, the numbers are still very high, and sub-occupation (mainly people with governmental social plans) was 13 percent in 2005. In this context, the solidarity of relatives and neighbors who are suffering the same conditions is limited.

The pensions are seen as a legitimate State intervention that makes life possible in that socio-economical context. None of the ex-patients from Clovera Hospital participating in this research have a permanent full time job that allows him/her to live entirely from that income. Sofía, who lives with María and Mercedes in a *casa de convivencia*, has have the same part time job as housekeeping for several years, but the money is not enough for a living, and she is always looking for something else. Pino also has had his job as seller of plastic bags from a Hospital workshop for more than 15 years; but the pay is also not enough. The jobs that most of the ex-patients have are temporary, irregular, or “*changas*” (occasional jobs). Examples of these *changas* are Celeste washing the cloth of an in-patient men once a week, Ayilin occasionally selling on the streets the bijouterie made by her, María selling AVON cosmetic products or baby cloth, Pedro picking up strawberries, Rodrigo selling at the farm post in the Hospital or making and selling popcorn at a school door, Celeste and María cleaning houses per hour, etc.

I understand ex-patients involvement in this kind of jobs as positive. I do not mean that these jobs are dignified activities or activities appropriate for them as mentally ill people. But they belong to a low socio-economical sector of Argentinean society, they are part of a larger population who may not have finished even primary school, and who also does such kind of *changas* for their living. Thinking that these form of life is not appropriated and that ex-patients are better cared interned in the Hospital is wrong. They prefer to live outside even the bad material conditions in which they live, because doing that they are not unique but part of popular sectors that live like them, trying to survive doing any kind of things. When

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<sup>65</sup> INDEC (National Institute of Statistics and Censuses): [www.indec.mecon.gov.ar](http://www.indec.mecon.gov.ar), consulted April 25, 2006

evaluating their deinstitutionalization we should contextualize this poverty as characteristic that, depending on where they live, make ex-patients equal to other people or not. When Davison et al (1995) describes ex-patients' life in New Haven and point out their dissatisfaction with community living in areas such as unemployment or inadequate housing, he does not see that these are also common disaffections to people who are not ex-hospital patients but who live in poverty in the New Haven out of Yale University campus. When judging the value of deinstitutionalization, as the authors do introducing the debate about "whether there is an abiding need of asylum and sanctuary for the seriously disable" (122), we should not consider the possibility of poverty and bad objective quality of life in the outside world as a factor for re-institutionalize or not de-institutionalize patients. Because it may lead to the idea, happily not shared by Davison and colleagues, that it is better to have the mentally ill care in madhouses than being poor in the community. This is a paralyzing argument for any kind of *externación* policy. The right argument might be that good material conditions and employment opportunities must be given to the mentally ill deinstitutionalized, as well as to the regular poor population. The problem should be solved improving community life conditions, and not "securing" the labeled mentally ill in institutions.

An important point is that, regardless their economical situation, the ex-patients do not loose their health treatment after being *externados* from the Hospital, because it is free and not depending on social security. The ex-patients are, among other marginals, in better conditions than other people since they are holders of subsidies or benefits. They can be seen, in this sense, as privileged (as a young woman from Roberto and Celeste's church told me, and as some other people think). Ex-patients understand this and feel more protected than other people. This protection does not come only from State subsidies but from the Hospital itself and the *externación* programs depending on the institution. I observed that Rodrigo and Celeste, for example, share their "privileges" with other people, spending their money from subsidies and pensions in taking the girls who live in front of their house to walk, to the zoo,

to the city, and they buy hotdogs, cokes, bus and train tickets and other things for them; taking one of the girls who had a health emergency to a hospital in a taxi; buy things to the patients who are still in the Hospital; or helping their relatives (Rodrigo paid half of her ex-wife funeral to help his sons with this charges, for instance). They also share the food they receive from the Hospital with *la señora* and give some of the supplies to their church so they can make *empanadas* or *tortas fritas* for giving to the patients at the Hospital. As I understand all these actions, they redistribute State benefits, constructing a life in which the psychiatric sphere and the outside world are mixed.

Ex-patients use social security pension or other subsidies as part of their survival strategies, and they do not really believe that they are permanently disabled for work. As I have observed, they are concerned about their future but they have hope and are optimistic about “making it” without having to do it “crazily”, in Estroff (1981) terms. In the same way, they make use of institution resources (social contacts, material objects, multiple services, etc.) in the same manner that Lis and Soly (1990) describe the nineteenth Century poor actively incorporating coercive total institutions into their survival strategies “subverting the instruments of labor regulation and social control into means towards their own ends”( Lis and Soly 1990: 37). As the poor described by these authors in the nineteenth Century, ex-patients (as well as patients) “take advantage of the hospital” (1990:53). As Lis and Soly say, the relations between state and civil society cannot be defined in terms of either coercion or consensus because social reality is more complex than that.

I only noticed a problem with the paralyzing aspect of social security when ex-patients hold several of these benefits at the same time (what supposedly is not legal). Rodrigo and Celeste, for example, both have national pensions and a subsidy, and together they make a considerable amount of money. As a consequence, I did not see Rodrigo concerned about working as I saw him before he got the pension. This observation, however, has to be seen in relation to Rodrigo and Celeste age. They are not old but they are close to the retirement age

(they are in their middle-late fifties) and their motivation for work may not be the same as that of a thirty or forty years-old person. For most of the ex-patients from my research, having a pension or a subsidy is just money that helps in their survival strategies, not just *the* strategy.

As Robert Wilton (2004) argues, the “welfare dependency” should not be solved by cutting these assistance, because that money help to solve the problems that mentally ill people find in the community, where material deprivation poses a greater challenge than mental illness. As Wilton says and as I could observe, it is important for ex-patients to count on some money allowing them to give and participate in reciprocal social relationships. However, we also have to know that welfare programs will never really make a change in ex-patients powerlessness lives. Welfare programs, as Stack (1974) demonstrates, are never designed for taken people out of poverty and of powerless positions in our society.

Close examination of the welfare laws and policies relating to public assistance show that these programs systematically tend to reduce the possibility of social mobility. . . . Welfare programs merely act as flexible mechanisms to alleviate the more obvious symptoms of poverty while inching forward just enough to purchase acquiescence and silence on the part of the members of the class [the poor]and their liberal supporters(Stack 1974:127).

Poverty itself is not a barrier to participation in social life, because poor people (ex-patients among them) only can survive socially (Lomnitz 1977, Stack 1974). But the subsidies and pensions, even not taking them out of poverty and even generating dependency, allow them to have something to give in this social participation. For a real change in ex-patients lives, as well as in other poor people lives, however, policies based on a recognition of their situation as product of the injustices of the anti-humanitarian market-centered reality in which we all are involved is needed (Gallardo 2000) They do not deserve the charity that we give to an “other”, they deserve being included in an “us” (in the community).

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We saw different levels in which deinstitutionalization can be analyzed and criticized as it has been implemented in different countries. From the obvious and visible abandonment

of patients after hospital closure (the homeless problem); their transfer to another institutions (tras-institutionalization); their placement in the community but without any change in how they are view and treat by the staff , and lack of professionals and family's believe in recovery and interest in patient's subjectivity (des-hospitalization keeping institutional ideas about the mentally ill); to the requirement to remain disable for obtaining social security benefits that encourage the maintenance of a psychiatric and stigmatized identity (having the institution inside). Nurses and doctors in the Hospital, nursing homes employees, volunteer staff in community residential facilities, income maintenance programs, authorities, family, there is always one of them remembering the ex-patient that she/he is disable and not able to have a valued social role. There is always somebody who does not believe in ex-patients possibility of recovery, and content themselves giving relief to material and health conditions. But for being really discharged of their "patient" role, people need more than relief. As consumers in the United States advocate, they need more than supported or sheltered employment; they need to be viewed with respect as valued persons.

The ex-patients of Egidio Clovera, according to the description I made of their lives, are not in a position of power, do not have good jobs, are poor, depend on the Hospital for many reasons, and are still part of a "psychiatric sphere". However, they are not completely powerless and their self esteem is pretty good. They are not passive dependants but they make domestic choices, have projects for their future, make an active use of Hospital resources, engage in daily survival strategies, construct social relationships and are not view just as "patients" but as valued friends, coreligionists, clients, babysitters, couples, and other many roles. Their lives are no "stark, empty, lonely, and tragic . . . monotonous and dreary" as Davison et al (1995:125) find the lives of twelve ex<sup>66</sup>-patients who returned to the

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<sup>66</sup> The authors continue to use the term "patients" for those deinstitutionalized persons who do not have any more this stigmatized role and identity because they are not hospital interned patients any more. Estroff (1995) criticizes the authors for their underlying conceptual assumptions calling these people with so stigmatizing term. When the term "patient" is used for psychiatric hospital ones, it is linked to a unique role and identity, and the authors do not recognize that.

community in New Haven. How can lives of ex-psychiatric patients who have the same diagnoses and the approximately same length of stay in the Hospital be so different?

The patients participating on the PSRC program and *externados* from Clovera are those long-term psychiatric patients with not strong dependency and more willingness to leave the Hospital, the first patients chosen for *externación* from the chronic population of a psychiatric hospital. Even though equally diagnosed (mainly with schizophrenia) and equally long-term hospitalized, the patients from Davison's study belong to the "second round" of deinstitutionalization in the United States during the 1990's, which focuses on the discharge of those remaining patients from the previous phases of deinstitutionalization. These people may be more emotionally distressed and may have less hope and belief in their recovery than those patients who have the challenge, the pride of being "the pioneers", fact that gives them hope and belief. Besides that, the ex-patients of my research do not experience many of the negative things associated with deinstitutionalization in other places. They did not find attitudes of rejection in the community; they have health professionals encouraging their search for a new identity different from the patient identity and who believe that they can have a normal life in the community; they were not obligated to leave the Hospital because its closure, as happened in other places; they could choose to leave and were led to live alone or with peers, with no control of their daily lives; they rely only partially on social security for their survival, and in general they make use of the benefits without really feeling handicapped; they believe that they can work, but they understand that it is difficult because of their age and the lack of employment, and because there is social discrimination toward giving a job to an ex-hospital patient. They do not define this discrimination as based on their illness but on the stigma associated by "outsiders" to the Hospital from which they come from.

**Chapter 7**  
**Some Conclusions: The *Externación* Programs, the Deinstitutionalizing Experience of the Ex-Patients, and the Place of Egidio Clovera Hospital**

The *externación* programs (Psychosocial Rehabilitation Center, Day Hospital, and Pre-Discharge House and *casas de convivencia*) are not projects designed from the health authorities or even from the Hospital authorities. They have been planned and implemented by health professionals, mainly female psychiatrists and psychologists, who had worked for Clovera Hospital for many years. They are independent one from each other, but they share a psychosocial approach to psychiatry focused on the person and her context and not in the patients' disease as an individual problem. In this sense, the programs (and the mental health professionals running them) differ from the traditional approach to psychiatry common in psychiatric hospitals and dominant in Egidio Clovera. The programs started "from the grass," from the needs of changes observed during the work in an asylum dominated by traditional psychiatry.

This beginning has pros and cons. In one hand, they are not based on external impositions and quickly exigencies of discharge for hospital closure, and they do not comprise practices seen as not needed by the hospital workers as it happened in other places where deinstitutionalization was implemented. On the other hand, they do not have the Hospital support for a policy of change in the whole institution, and even for a development of the programs themselves, which survive in a constant fight for resources, personnel and complete official recognition. The existence of the *externación* programs inside the neuropsychiatric Hospital is highly positive and needed, but they are also highly vulnerable, because they rely on the personal support of the Director of the Hospital. The low budget given to the programs reflexes the low consideration for them in the mental health policy of the Hospital, but of course, the institution is not alone in this lack of interest in a mental health transformation; the mental Health policy of the entire Province exhibit few consistent novelties.

Besides their deficient budget and personnel, the programs lack integration and the support of a compromised mental health policy for the Hospital as a whole. They are islands in a medical space that is fragmented and missing a clear objective. The health professionals running the programs feel that they are resisting, fighting against a *manicomio* that allows them to exist but only under its control. The *externación* programs can be seen as escape valves for the old psychiatric hospital system, but from the patients' perspective they are a hope, a real possibility to be heard and given an opportunity to leave the institution. Only a few patients are implicated in the programs, but the present *externación* programs have a revolutionary impact on them, who used to be chronic long-stay inpatients.

Ex-patients highly value all the *externación* programs. Regarding the PSRC, it is viewed by patients and ex-patients as a place for a real rehabilitation focused on real possibilities of *externación*. The program *casas de convivencia* is often the only one offering housing after *externación*, and it is also very valued by the patients. From the ex-patients' point of view it is clear that the PSRC and *casas de convivencia* are needed and successful. What is also clear is that there is more need of programs like the PSRC and more *casas de convivencia*. Many "chronic" patients and sub acute ones are waiting to get in the PSRC in order to go to a *casa de convivencia*, but there is no place for all of them, and there are not enough *casas*.

Also, I see that more work is needed regarding medication. Ex-patients participated in the past on a workshop at the PSRC about knowing and managing their medication, but more workshops are needed around a theme that is untouchable and keeps ex-patients, in some way, dominated under the fear of going back to the Hospital if they do not take their medication. The approach of the programs is psychosocial, but they also give importance to medication to enabling patients to live in the community. I heard many times from professionals and ex-patients that dropping on medication is one of the main causes of re-hospitalization. Of course, after decades of taking drugs it is probably not possible to leave them and ex-patients

have certain dependence on it. But more work can be done about information, side effects, possibility of discuss doses, etc. Patients and ex-patients at the programs are having psychological therapy accompanying the psychopharmacological treatment, and they have medication controls. This makes a difference from other deinstitutionalization programs where ex-patients are just under medication without any therapy (Mac Court Perring 1993), and sometimes without any checking and control of their doses by a psychiatrist for years (Swartz and MacGregor 2002). Professionals at the PSRC, also, do not take for granted the diagnoses of patients who arrived at the Center. Patients may have been labeled with a diagnosis twenty years ago, but psychologists and psychiatrists discuss it in a team. Different from many wards at the Hospital that do not have a psychologist or other health professional besides a psychiatrist, at the PSRC there is a team. There is a need, however, of paid social workers and occupational therapists, and I think that a peer support group can be organized at the PSRC. Some ex-patients whose recovery has been successful may be also hired to work at the PSRC, sharing their experiences with patients and workings on their self-esteem and hope, as consumers started to do in the United States.

The programs are independent one from another, and strongly dependent on the few Hospital professionals who designed them. This fact makes health professionals from other Hospital dependences criticize the programs as focused on personal interests and ideas. They are personal projects in fact, but this does not mean that many other Hospital workers cannot share the same ideas and expand the programs in order to integrate more patients. The programs lack articulation with the rest of the institution and between them, even there are some integration between the Psychosocial Rehabilitation Center (PSRC) and some of the activities of the Pre-Discharge House (P-DH) (especially the program *casas de convivencia* administered by the *P-DH*). Working in a better articulation, the PSRC and the P-DH's professionals disagree about different issues, such as the criteria for patients' selection for the programs. Pre Discharge, for instance, does not accept couples for the *casas de convivencia*,

but professionals at the PSRC think that it is positive for some patients to leave Clovera as a couple, together. As Mariana, psychologist from the PSRC told me, “I think that they function better when they have a couple, at a contention level.” Also, the Pre-Discharge program has very strict criteria for selection of patients, while the PSRC does not. But as every rule has exceptions, the two programs make their conditions more flexibly. Otherwise, some of the ex-patients of this research would not be in a *casa de convivencia*.

The PSRC, where the ex-patients who participate on this research were interned before their *externación* and where I did more observations than in other programs, is a program where patients and ex-patients are seen and treated more respectful than in other Hospital dependences. I saw Alicia and Julieta greeting patients with a kiss, and discussing issues with them in a much more horizontal relationship than the common doctor-patient relationship. However, it is difficult to change the patients’ inferior position leaned during so many years of internment. Some ex-patients confront their doctors and discuss issues with them in a relatively equal position, but others remain submissive and expecting “control.” Their powerless status, however, is not only a product of physicians’ and institutional oppression. Even erasing these oppressions, ex-patients have inferior education, social and economical resources. Their empowerment from their psychiatric condition as disable, incapable, and permanently ill has to be measured in their interactions with people who are their equals. In their neighborhood, Celeste and Rodrigo are as powerful as their neighbors.

\* \* \*

The programs I described in this thesis, with especial emphasis on the PSRC, are full of people with enthusiasm and energy, Hospital workers and also university students and graduates that know that a more humanitarian treatment is possible. They strongly contrast with the mediocrity and flatness that I saw among the professionals and employees of some of the chronic wards. Patients are encouraged to abandon their institutionalized characteristics and to think about themselves as valued people who can recover and re-integrate into the

mainstream society. Ex-patients or new “ambulatory patients” are encouraged to keep themselves in the community and to do a life as normal as possible. I just hope that these programs are only the first step towards a new manner of viewing and doing mental health care in the totality of the Hospital, if not without it.

There is especially one aspect of the PSRC and the Day Hospital programs that generates ambiguities, related to the relation among the Hospital world and the life in the community. The programs’ characteristics correspond with the kind of services commonly viewed elsewhere as part of a community-based mental health care system, opposed and alternative to the psychiatric hospital. But they are located inside the Hospital; they belong to the Hospital, emerged from inside the Hospital, and are alternatives linked to the Hospital. Ex-patients have been *externados* and placed on the community, but there is not a community mental health care system available for them there, beyond the Pre-Discharge House (which also depends on Clovera Hospital). Ex-patients are told to separate themselves from Clovera while having to go there for treatment and to pick-up the food supplies. Independence is encouraged but at the same time it is recognized that ex-patients have close bonds with people at the Hospital, especially boyfriends/girlfriends, and this is approved by professionals of the Center. Regarding the P-DH that is located outside the Hospital, professionals and other employees complain that it is used as a drop-in center by ex-patients who live in *pensión*’s rooms in the city, and that they are reproducing a hospital’s ward-like environment in the community. They encourage ex-patients not to spend their time there, even though they have to go there for their daily meals. “My doctor tells me that I don’t have to go to Pre-Discharge all the time. She says that she doesn’t want to see me there any more,” told me Ayilin.

Ex-patients’ use of the P-DH may suggest the need of a facility where ex-patients met each other and interact. A space where to share experiences as a peer support group may be useful, and I already suggested that more active participation of ex-patients in the PSRC would be positive. I find especially positive the interaction created by visiting, as Pino does

going to the houses of Rodrigo and Celeste, Maria and the other women, and also other *casas de convivencia*. The problem is that the ex-patients who spend the day at the P-DH are mostly those who, as Ayilin, live in a *pensión* room in the center of the main city. A room in a *pensión* is not the most adequate place for visiting. When I visited Ayilin we sat in her bed, and she could not offer me anything to drink unless she had hot water in her thermo to prepare *mate*. A *casa de convivencia* or in independently rented apartments or houses (as where Celeste and Rodrigo live and where Mariano and Ester have just moved) allow to have a more comfortable place to receive visits. Again, I think that there are other cheap independent housing options alternative to a *pensión* room, and located in neighborhoods where ex-patients feel more comfortable and “fit” better.

The idea behind the expectation of ex-patients detaching themselves from the institution and from the P-DH is that they should not remain in a psychiatric sphere but should integrate into the outside society. But the psychiatric sphere should not be seen as completely isolated from the outside world; ex-patients do not make this difference. From a totally different position (that of being free for make choices, have privacy, be free of the controls of a Hospital ward), ex-patients are, however, in a continuum between Hospital and community life. For them, it is possible to have friends among ex-patients and patients as well as among people who has no psychiatric conditions, and it is possible to do normal things (to be present and to use the community resources) while at the same time participate in the “psychiatric world.” It would be needed is a higher politization of the deinstitutionalization movement to create more social conscience and acceptance of people with psychiatric conditions living as citizens and being able to share their psychiatric world with the outside one without stigma, making available for them to have a normal life in a wider conception of normality. What is important is not that ex-patients maintain themselves far from the institution, and avoid seeing other ex-patients; what is important is their construction of a new identity from where to relate with others not as passive powerless receptors but as persons with self-esteem, own projects,

and determination that makes use of the institution instead of being managed by it. As I see it, having a partner and being the partner of another person, no matter if he/she is a patient, ex-patient, or someone outside the psychiatric circle, gives patients and ex-patients a social role, a valued role difficult to find for many “normal” people, and it is a big step towards their recovery.

I described the ex- patients from Egidio Clovera Hospital as socially active persons and engaged in productive activities and works, with a relatively high integration into the mainstream society. As I see this integration, no distinction is needed among psychiatric or non psychiatric social life, work life, or pleasure life. Most of ex-patients live a normal life in which they rely on the Hospital for many of their needs, as other people rely in other institutions and the resources they offer, such as churches, universities, companies, etc. Many people are insiders in special worlds while at the same time are part of the mainstream society. But a change in the stigmatized way in which society sees everything that is “psychiatric” is needed for a better acceptance of this kind of integration.

The psychiatric hospital has been criticized and condemned for its institutionalizing effects, for being “total institutions” of confinement, discipline, control and punishment (Dunham and Weinberg 1960; Goffman 1962; Foucault 1989). But institutions are more than instituted norms and order, they are also instituting by daily experiences, productions and meanings (Lourau 1994). In the friction between formality and informality, patients and ex-patients are not just receptors of oppression but they, together with low employees and neighbors, construct the Hospital space beyond its medical meaning and rules, making it a multiple resource. Therefore, we should see more than institutionalism in ex-patients attachment to the Hospital. Their dependence on the Hospital has its logic, as well as neighbor-employees dependence on the Hospital has. In the informal economy constructed in the Hospital by employees and patients, rules, norms, and official functions have fissures filled with informal social relationships, management of resources, and execution of norms

and functions. Ex-patients are part of this informal economy and will continue to make use of it, at least until they construct a completely new life detached from the Hospital/resource.

We should not understand, at least in this moment and in the ex-patients context, community and Hospital as two complete opposite configurations. Studies of hospital life suggest that a hospital “is a world apart, a culture which is altogether different from the ‘real’ world or even a reversal of normal life” (van der Geest and Finkler 2004: 1998). But hospitals and communities are not homogeneous everywhere, they have their particularities. As van der Geest and Finkler (2004) say, the broader social and cultural process is played out in hospitals, which are not identical everywhere, there is a variety of hospital cultures in different countries. Egidio Clovera is a particular institution that is not completely closed and is more than what its official aim states for those who interact in it and who socially construct its space. It is not solely linked to medicine; in its socio historic and economic context it serves other missions for whom actively and productively make use of it. Why to require ex-patients to forget this world and to start over with nothing?

In other places, it has happened that the new community services offered to patients as alternatives to hospitalization were seen as so different that no articulation or joint planning were done between the two systems, and patients suffered their transfer to one place to the other (McCourt Perring 1993). But as Mariana told me, patients are persons, and they constructed social relationships and roles during all the years they spent interned. It is not possible to blow it up and start a new thing as if they were just objects, especially if there are no services in community.

\* \* \*

The community-based system of mental health care linked to deinstitutionalization in other countries does not exist in Buenos Aires province. The ex-patients from Clovera are not care in the community -with the exception of those who are treated at the Pre discharge House in the inner city-. But can we say, from the analysis of deinstitutionalization elsewhere and the

description of the *externación* programs and ex-patients experiences in Buenos Aires, that Celeste, María, Pino, Rodrigo, Ayilin and the others have been deinstitutionalized? The ex-patients have been des-hospitalized, they are not interned any more and live in the community; they have been given back their right to be citizens instead of being excluded from society. And a subjective sense of deinstitutionalization has been achieved by ex-patients, in more or less degree. They could manage to integrate in their new neighborhoods instead of remaining isolated and enclosed in their houses. The “asylum without walls” described by Dear and Tylor (1982) in neighborhoods in the United States is not the situation that I have observed in Argentina. Ex-patients are as present and as other people in their neighborhoods, even though in some neighborhoods is more easy to feel integrate than in others, as we have seen. They are confident in themselves, proud of their achievements, and concerned by the same problems than other not mentally ill people: how to make a living, find a job, planning the future. They only use their “sickness role” for convenience, but do not act and believe in that role any more. Instead, they want to give, to construct reciprocal relationships, and not to be mere passive recipients. They have self-respect, take choices, and have autonomy. The most difficult to achieve aspect of ex-patients’ deinstitutionalization is their empowerment. As I see the issue, it is not only difficult for them to get empowerment because of their many years being “patients” but also because of their poverty, lack of education and family, and their marginal situation with respect to the industrial economy. As always, those with more attitudes of solidarity and acceptance are the poor, those who share the same powerlessness and marginality.

Ex-patients have not totally left the Hospital world and they still have aspects of the institution inside and institution-like costumes (such as Sofía not drinking *mate* with professionals, or Mercedes and Ayilin locking their closets or night tables, or Celeste asking for “control.”). Most of them still rely on Hospital relationships as a main resource for their social, affective, material, and medical needs; and they participate in sheltered activities. But

most of them do it actively and consciously, not submissively, and they also construct relationships with non-hospital related people, combining the psychiatric and the outside world, showing that an heterogeneous society is possible. As activist consumers in the United States showed me, “it is possible to recover and to have a full participative life in the community, where we are all different but we don’t have to be separated”(Daniel Fisher, October 19th 2005). In the United States, however, the deinstitutionalization experience of many psychiatric ex-patients since the beginning of the deinstitutionalization process in the 1960’s was marked by homelessness, abandonment, and social rejection. Where psychiatric Hospitals closed, the scarcity of community-based services, social networks, and housing facilities was no supplemented by a hospital constructed as a resource such as Egidio Clovera is. Only in the last decade the mental health community services developed and started to fulfill ex-patients needs. In Buenos Aires Province, on the contrary, the *externación* experience of the ex-patients is being accomplished without a sudden loss of the social relationships constructed inside the institution and the resources obtained from there; the communities where ex-patients are living accept them and incorporate them, and ex-patients participate in the community especially well when they are in a socio-economically similar situation than their neighbors. The good objective material condition of houses and neighborhoods is not necessarily accompanied by a good social interaction and integration of ex-patients in their neighborhoods. The place where Celeste and Rodrigo live is materially deprived, but it is full of social life and neighbor domestic networks in which they participate as socially valued actors.

These ex-patients, successfully *externados* from a psychiatric hospital, are only some of the thousands interned in psychiatric hospitals in Argentina. It is uncertain whether or not Buenos Aires province will take the political decision to close the psychiatric hospitals and transform the metal health care system. If it happens, then we will see how Argentineans face the *convivencia* with those of its members for so long excluded, whether with policies focused

on what charity demands or on what solidarity requires in the sense of inclusiveness (Hooper 2003). Meanwhile, and slowly, long-term psychiatric inpatients diagnosed with serious mental illness are coming out from the mental hospitals and constructing by themselves their place in society. They have the job to show psychiatric patients, health workers, and the mainstream society that the “experiment” works, that recovery and participation in society from a respected and valued role is difficult but, possible no matter how many years they have been kept out.

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## Appendix: Glossary

### Manicomio:

Asylum, called today with the less stigmatized name of psychiatry hospital or mental hospital

### Institutionalism:

Process occurred to persons interned for a long time in institutions such as a psychiatric hospital. It implies the loss of a previous identity and the development of an identity of "patient."

### Patient:

Person interned in the chronic sector of psychiatric hospitals whose unique recognized identity is that of patienthood, and that is considered a constellation of symptoms instead of a person, an individual with a disease instead of someone with a social context, history, and problems. Patients are usually considered passive, powerless, flat, unproductive.

### Consumer:

A term chosen by people diagnosed with mental illness in the United States to refer to themselves in a way different from the stigmatized "patient". It means that they are active "consumers of mental health services," and not of receptors of them.

### Deinstitutionalization (or desmanicomialization):

Process linked to a change from hospital-centered psychiatry to community-based psychiatry (day hospitals, half-way houses, counseling, psychiatric services in general hospitals, group homes, sheltered workshops, etc). Deinstitutionalization in a subjective level refers to the removal of an institutionalized and stigmatized identity of patienthood and the restoration of self respect, self esteem, and a new identity associated with a socially valued role.

### Traditional psychiatry:

It is the psychiatry centered in the psychiatric hospital as the place for treatment and care of the mentally ill. It is mostly biologically oriented instead of socially oriented.

### Community-based mental health care:

Is the psychiatric system alternative to the psychiatric hospital. It is based on facilities and services offered to the mentally ill in the community without need of long-term internment and segregation from society.

### Externación:

Term used in Argentina to refer to the process of psychiatric patients moving out from the hospital to the community, but continuing with the psychiatric and psychological treatment at the hospital. It can imply a definitive medical and judicial discharge of the patient or only weekly removable discharge. It is not deinstitutionalization in the sense of going from hospital to community services, but it may imply deinstitutionalization in the subjective level

### Recovery:

Concept that started to be accepted in psychiatry in the last years and that is different from remission and rehabilitation. It implies that a person diagnosed with a severe mental illness (such as schizophrenia or manic-depression) can recover a full life: the capability of making their own decisions, having a social role, choosing their mental health services, having meaningful social relationships, having control over their life and emotions, function pretty well. It also implies empowerment and that non trained people do not consider them sick.

### Normalization:

Has two different meanings: the first meaning refers to ex-patients adaptation to socially accepted behaviors, values, rules, activities, etc. in order to "pass" as "normal" in society. A different meaning of the concept refers to making available for ex-patients an environment in which they can have a life as normal as possible.

### Crisis de nervios:

Folk category used by Latinos for referring to emotional distress (what psychiatry call mental illness) that is less stigmatized than a psychiatric label and implies a future recovery. Crisis de nervios is an idiom to express dislocations of the social and family world as well as economical and many other problems, and that expresses with different symptoms in body and behavior (screaming uncontrollably, breaking things, fainting, attacks of crying, trembling, becoming verbally or physically aggressive, etc.)

Autovalimiento:

Self-help: being able to dress, cook, wash, etc. by oneself.

Autonomía:

Autonomy, self-sufficiency: having a job or a pension that provide income, being able to make own decisions, going to the bank, making proceedings, using the public services such as the bus system, managing oneself in the city or neighborhood, etc. without depending on other people or institutions.

Psychiatric sphere:

Or “psychiatric world,” the social and material resources related to the psychiatric hospital or to the community mental health services, where ex-patients, patients, health professionals, and also other employees (administrative, maintenance, teachers, etc) and people related to them (relatives, neighbors) participate.

Outside world:

The “community” of people, places, and resources not related to the psychiatric sphere

NIMBY “not in my back yard”:

Attitude of rejection towards ex-patients and the opening of mental health facilities in the community developed with the fast closure of psychiatric hospitals with deinstitutionalization in the U.S.

Pensión:

Large old house with many rooms for rent, kind of boarding house with no staff where some ex-patients and other poor people live in Argentina

EXTERNACIÓN PROGRAMS OF EGIDIO CLOVERA HOSPITAL:

Day Hospital:

Project developed by a psychologist from Clovera Hospital in 1995 and run mostly by Ad-Honorem volunteers. It functions in a building inside the Hospital and offers 6 to 8 month treatment with individual and group psychotherapy and daily workshops. Destined mostly to young people with some family support and several institutionalizations. Oriented to avoid re-institutionalization and to achieve a participative life in the neighborhood, in a social group, and in the family.

Pre-Discharge House:

Facility that belongs to the Hospital but is located in the center of the city. Opened in the late 1980's and has change over the time. Presently offers productive and artistic workshops and therapy for ex-patients *externados* (living outside the Hospital) and also for some patients close to being *externados* or discharged, and supervision of *casas de convivencia*

Casas de Convivencia

Program supervised by the Pre-Discharge House of the hospital consisting in houses or apartments rented by the Hospital in different near neighborhoods where three or four ex-patients live alone temporarily until they have the means for moving by themselves.

Psychosocial Rehabilitation Center (PSRC)

Program designed and implemented by two psychologists and two psychiatrists of the hospital. Opened in 2001 in a building inside the Hospital. Houses around twenty female and male patients and rehabilitate them for being *externados* and for having a medical and judicial discharge.

P.R.E.A:

*Programa de Rehabilitación y externación asistida* (program of assisted rehabilitation and *externación*). Program of the health Ministry of Buenos Aires Province that appeared in 2000 promoting *externación* of psychiatric inpatients and recognizing *casas de convivencia* as a housing option. PREA has been applied fully in only one psychiatric hospital.

INCOME MAINTENANCE GOVERNMENTAL PROGRAMS:

*Pensión Nacional por Invalidez* (national pension for incapacity)

Monthly small stipend given by the national Human Developing Ministry to deprived people with no income, material goods, or any kind of income and who have a 76% of incapability for work. Once given, it is for life.

Program “Vuelta a casa” (back home)

Monthly small stipend renewed every six month given temporarily by the government to ex-patients *externados* from psychiatric hospitals

Subsidio para externación de enfermos mentales (subsidy for externación of mentally ill people)

Monthly small stipend renewed every six month given temporarily by the Provincial Supreme Court of Justice to ex-patients *externados* who are represented by a curator from the “Curaduría Oficial de Alienados” (State guardianship of mentally ill) of the Justice.

Plan “Barrios Bonaerenses” and plan “Jefas y Jefes de Hogar”

Governmental Plans for unemployed people created during the 1990’s in Buenos Aires province. Holders receive a monthly small stipend in exchange of part-time work doing different tasks.

INSTITUTIONS:

Integration Council for handicapped people (Consejo de Integración del Discapacitado)

Local institution (belonging to the city government) that offers productive and artistic workshops for people with different kinds of disabilities.

Provincial Health Ministry:

The main health authority at a provincial level

Curaduría Oficial de Alienados:

(State guardianship of mentally ill). Office of the Judicial System in charged of representing those psychiatric patients with a trial for *insanía* (insanity, dementia) or *inhabilitación* (incapability, disability).

## **Vita**

Erica Dillon was born in La Plata, Argentina, in 1973. She graduated in 1992 from the Fine Arts high school at National University of La Plata, where she received a degree in music education for children. While teaching music in several public schools, she studied at National University of La Plata and received a bachelor degree in history in 2000. In 2001, Erica decided to explore anthropology enrolling in a master's program in social anthropology at San Martin University, Buenos Aires, while simultaneously teaching history and music at public schools.

Erica was interest in the meanings of public institutions for those who daily interact in them, and she focused her research in a centenary neuropsychiatric hospital where she did fieldwork during 2002 and 2003. She became concerned about the mental health system of care in Argentina and fascinated with the ethnographic methodology for its study.

In September 2003 Erica moved with her husband to the United States. Desiring to continue her research, this time focused on new possibilities of transformation of the Argentinean mental health system, Erica entered a master's program in anthropology at Louisiana State University in 2004. In summer 2005 she traveled to Argentina to defend her thesis at San Martin University and completed the fieldwork for her research at LSU.

After graduating from LSU in summer 2006, Erica hopes to dedicate researching in applied clinical anthropology, and eventually she plans to enroll in a doctoral program.