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## **NOTE TO USERS**

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**Being Ill with the Disease of Schizophrenia**

**Mark Paulse**

A Thesis

in

The Department

of

Sociology and Anthropology

Presented in Partial Fulfilment of the Requirements  
for the Degree of Master of Arts at  
Concordia University  
Montreal, Quebec, Canada

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## **ABSTRACT**

### **Being Ill with the Disease of Schizophrenia**

**Mark Paulse**

This study is an ethnographic exploration of deinstitutionalised schizophrenics in Montreal. The focus of this paper is how schizophrenics and their primary caregivers have come to understand and reinterpret schizophrenia in an era of post-institutionalisation. The emphasis of this paper is on how Quebec's *virage ambulatoire* has seen the shift in responsibility for the psychiatrically ill from psychiatrists to community care workers and the schizophrenics themselves. In addition to the historical development of institutionalisation and deinstitutionalisation this work includes a description of the places schizophrenics have come to rely upon in the wake of closed asylum beds. Other issues to be addressed are; the conflict between objective disease and subjective illness; agency, psychiatric non-compliance and social non-conformity; concepts of wellness and chronic illness; and the utility of a psychiatric diagnosis in augmenting benefits and accessing services. Because of the exploratory nature of the study, conclusions are formulated in terms of further work to be accomplished and different epistemological tools to be developed to better understand the situation.

## **Dedication**

This thesis is dedicated to those about whom it is written. After all, without their help, this would simply be stationary.

The work that this thesis represents would not have been possible without the support of the research team of which I was a part. In particular I would like to acknowledge Dr. Caroline Knowles, Pascale, Norva and Stephanie for their leadership, help and support. I would also like to thank my thesis advisor, Dr. Dominique Legros, as well as my defence committee members, Dr. Christine Jourdan and Dr. Marie-Natalie Leblanc.

And because misery loves company, I acknowledge the support of Concordia University's first MA cohort in Social and Cultural Anthropology. In particular there was James McDougall who suffered (and drank) the most with me, Kimiko Hawkes who proofed my first draft, Annie Lachance who kept encouraging me and Simone Lienhart on whose behalf I succeed. I also would like to thank Pandora Hobby who proofed various revisions and let me bounce ideas off her, Nikki Gilardoni who always let me know when it was time to buckle down ("You're almost 30!") and Josué Asselin who saw me through most of my struggles with this work.

There are also two people, Yaël Glück and Tracy Ford, who I often thought of during the writing of this work and would like to thank for having seen me through my undergraduate and on my way to my Masters.

This work is also partly the success of Susan Joe who always believed with me that it needed to be done and was important.

As a testament to the support of my family this thesis is dedicated to my family. My parents, Margaret and Dennis have made all things not only possible for me but often easier to attain. Michele inspires me through her own accomplishments and Melissa provided equal amounts of help and distraction. And what would have become of me without those breaks in Vancouver with Michael, Melanie, Ken, Sharon and Evan? I love you all.

Finally, this thesis as a personally significant achievement is dedicated to the memory of Alice Jacobus. She taught me many things.



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## Chapter 1 - An Introduction

*What we hope from social scientists is that they will act as interpreters for those with whom we are not sure how to talk.*

-- Richard Rorty, *Consequences of Pragmatism*

*What do I do during the day? Not much really. I know I have to stay because of the major. The major needs me. I like the major but he get into some awful mess. And I know if I don't stay I'm legitimately at war with Canada. And I don't want to announce ... I stole all of their police cars. They basically, I have a spaceship that could take it over. And turn it into a spaceship. I go pickup the angel on the road eh? All the angels, and there was a big fight in my house, everybody was shooting each other, and I gave the little girl, I gave my tree house windows, two of them. And I gave them army gun boots, and I gave them black gun boots. And they're priests. The eighteen year olds are like priests. Alright?*

-- "Eddie<sup>1</sup>," a schizophrenic informant

### **The Larger Project**

In 1996 I joined a research project funded by the conseil Quebecois de la recherche sociale and headed by Dr. Caroline Knowles at Concordia University. This research introduced me to the study of schizophrenia and facilitated different research around which this thesis is organised.

Generally the research team was attempting to better understand psychiatric care in non-specialised community settings<sup>2</sup>.

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<sup>1</sup> The names of all my informants and the places they worked or visited have all been changed in an effort to maintain confidentiality.

<sup>2</sup> Objectives were stated as follows: 1. Compare lived mental distress with the ways front line carers understand and administer it in non-specialised community services. 2. Look at the issue of belonging and identity embedded in lived experiences of the mentally distressed, especially compared to the social identities attributed to the mentally distressed by carers. 3. See what ethnicity and culture mean to those who take it into account in their lives and identities. To see if ethnicity and culture enter into the lived experiences of mental distress, belonging and identity, and how. See whether ethnicity and culture are significant social identities in the calculations of carers. 4. Assess what kind of community services are accessed by psychiatric patients and determine the demographics of community psychiatric patients. 5. Assemble results into a form usable by the participating agencies for staff training and look at other areas of service provisions with a view to improvement.

## **This Project**

Schizophrenia is a mental illness whose mosaic of symptoms seems to manifest itself in a variety of psychopathologies. For the social scientist it offers many opportunities for socio-cultural enquiry and analysis. How these psychopathologies are used to explain restrictions on, or opportunities for, the schizophrenic is one way in which different cultures and societies articulate their expectations of the mentally ill. What sort of role repertoires are left open for diagnosed schizophrenics and how do they fulfil these roles?

This work is, in very broad strokes, concerned with what it is like to live as a schizophrenic. In our current era that could aptly be described as one of post-institutionalisation, schizophrenics have been moved into the community. This move has meant that schizophrenia has come to be identified with a range of social problems beyond the scope of the disease itself. To be schizophrenic is as much to have a social role as it is to have a psychiatric diagnosis.

This role however, freed from the scrutiny, and restrictions of, institutionalisation may be negotiated. Schizophrenia is clinically defined by psychosis but deinstitutionalisation allows the schizophrenic to pursue understandings of his/her own disease in ways different from that of the clinician. Although particular psychotic episodes may be defined as schizophrenic, these episodes are likely to recur rather than persist. The intervening periods of recovery and wellness (or at least relatively high degrees of functionality) are also part of what it is to be schizophrenic despite the absence of schizophrenic episodes. It is this continuity (being schizophrenic), a sense of wellness in the midst of illness, with which this thesis focuses on as essential to understanding what schizophrenia is as a lived experience beyond that of a psychiatric diagnosis.

Keith Doubt, in wondering if there is a viable sick role for schizophrenics cites Talcott Parsons: "Participation in the social system is always potentially relevant to the state of illness, its etiology and to the conditions of successful therapy" (Parsons in Doubt, 1996: 5). The chronic nature of schizophrenia means that the 'sick role' is inseparable

from the schizophrenic's character. Coping with schizophrenia demands that the schizophrenic seizes certain opportunities and accepts certain restrictions as part of a valid effort to participate in a social system. General practitioners, psychiatrists, psychologists and social workers are a few of the people in charge of monitoring the validity of this effort. Deinstitutionalisation confronts the schizophrenic with a set of problems of which institutionalisation had formally taken care. Maintaining compliance with the medical treatment, finding housing, employment and making social contacts are some of these problems. These same issues are ones that expand the possibility for participation. How schizophrenics participate in the community after deinstitutionalisation becomes an expression of the sick role as schizophrenics themselves make choices in an effort to make do. Negotiating the web of social services left in the wake of deinstitutionalisation involves many choices. This thesis is interested in how schizophrenics understand their own disease, the role parameters (sick roles) within which they function and how schizophrenics use these to explain and improve their situations and to negotiate the web of social services.

These understandings however are derived as much from the personal experiences of being schizophrenic as from others' understandings of schizophrenia. Relying on either clinical definitions of schizophrenia as a psychiatric disorder or on self descriptions by schizophrenics (themselves often powerless and occasionally seen only as psychotics, who may for example, push waiting transit passengers onto the tracks in the Toronto subway) distort any understanding of the illness not least of all by juxtaposing two extremes.

### **Situating this Work (anthropologically)**

This section was intended mainly as a review of the literature pertinent to this work in an effort to situate this thesis within a body of (specifically anthropological) work. It is not surprising however that the topic of schizophrenia would enjoy a greater popularity among other disciplines (psychiatry, psychology and social work) than within anthropology making my task somewhat difficult. For example, a search for "schizophrenia" and "schizophrenic" of the *American Anthropologist* yielded one hit for the nineties. The

same search on the "Anthropological Index to Current Periodicals in the Museum of Mankind" yielded twenty-nine hits, most from journals dealing with human heredity, human genetics and human biology. What then is an anthropology of schizophrenia and how would one make cross-cultural comparisons?

Although there is a large body of work dedicated to labelling theory (Scheff 1966; Shur 1980) and stigmatisation (Goffman 1969), there has been little done dealing with such things as subjective beliefs about being mentally ill and the affect of institutionalisation (and deinstitutionalisation) on patients ideas about self (Lally, 1989: 254).

Many texts use patients' accounts to relate symptoms of schizophrenia and/or analyse case studies. Although this may blur the line between case study and ethnography, as far as they use professionals as primary informants and as the interpreters of schizophrenics they fall short of grappling with schizophrenia from a subjective view point (Torrey 1995; Bateson 1972; Devereux 1980). In addition these texts, similar to other informative texts such as those by Health Canada, seem to use schizophrenics as a unit of analysis for schizophrenia.

Academic writing on schizophrenia falls into two categories: medical and social. Medical writing is dominated by psychiatry (Andreason and Olsen 1982, Andreason 1984, 1990, Torrey 1995; Mendel 1996) and is useful for understanding clinical schizophrenia and the medical model informing community care. Social science concerns centre around marginalisation and stigmatisation (Knowles 1991, 1996, 1997; Murphy *et al.* 1988; Lewis *et al.* 1992; Sarbin and Mancuso 1980) and on community care including: the practice and goals of community psychiatry (Wasylenki *et al.* 1994; Marmor and Gill 1989, Macdonald 1997, 1998), criticism and support for community care (Bachrach 1994; Lamb 1988, 1993; Boyle 1990; Sasz 1970, 1974) and the treatment and follow-up studies of community-care programmes (Brown 1985, Corrigan and Liberman 1989; Conway *et al.* 1994; Goodwin 1997).

Despite early interest in the psychotic patient's insight in informing community care programmes (Herz and Melville, 1980) and the diverse ways by which patients influence the course of their disorders (Strauss *et al.*, 1978), in *Schizophrenia Bulletin's* edition on subjectivity and schizophrenia in 1989, Stephen Lally noted:

In general, there has been a neglect of the patient's perspectives, and there is very little information about how people with mental disorders cope with the challenges their hospitalization and symptoms present (Lally, 1989: 254).

Elsewhere in this edition of the *Schizophrenic Bulletin*, Strauss and Estroff wrote:

There is something seriously missing in the field of mental illness that does not attend closely and broadly to patients' subjective experiences and sense of self (Strauss and Estroff, 1989: 177).

They seemed to be etching out a spot for ethnography as a useful tool to reveal the subject as opposed to a psychiatric object.

The subjective experiences of schizophrenia and related disorders provide the primary basis both for understanding these disorders and for understanding the individuals who have them (*ibid.*).

Sue Estroff in fact believes that schizophrenia is an important topic for anthropologists. Chronic schizophrenia, cure and relapse pose questions about who gets ill and why and who does not get better, and why and what happens to and about them (Estroff, 1993: 247). Here not only can anthropologists offer insight and interpretation that aid in the healing process, but in these questions, there is also the *possibility* to account for culture (*ibid.*). Schizophrenia, a disease occurring cross culturally and generally with unified treatment, is not only accepted differently between cultures but indicates that there may be socio-cultural factors that affect curability.

Cultural anthropologists have employed ecologic, systems-theory points of view in examining disease (Kovel 1987; Fabrega 1989; Estroff 1993). Medical anthropology, being concerned with "sickness and healing," approaches the topic of schizophrenia as a phenomenon subject to different forms of cultural expression (Young 1982; Corin 1990). There seems to be no neat, specific place between these two that deploys ethnographic accounts of the mentally ill to confront medical assumptions in a historical period. Although



this thesis does not rely on maintain that schizophrenics are their own cultural group. it does use a sense of cultural temporality to account for shifts in cultural. This project then. is not necessarily a cross-cultural account. but rather still uses historical and political cultural influences to account for what is happening to and about schizophrenics amid changing approaches to treatment and care.

Psychosis has allowed for the assumption that those diagnosed with a psychotic disorder lack awareness. If it was true that the "psychopharmacological era" has meant "there has been little attention to whether a patient's insight into psychosis played more than a modest role in treatment or outcome" (Greenfeld *et al.*, 1989: 245) then it is almost ten years after the special edition of the *Schizophrenic Bulletin* that there began an understanding that narrative analysis of the "psychotic experience" is able to join "the aesthetics of storytelling. with it's metaphoric quality and capacity to evoke real and imagined worlds through sensory images and sensate feeling. and the analytic but dynamic treatment of social action as text" (Lovell, 1997: 355).

Much of the work dealing with schizophrenics continues to be subsumed into other works on marginalisation including general mental illness (Morris 1998: Barham 1997: Conrad 1987: Castell 1988: Sass 1992: Ingleby 1982) and homelessness (Dear and Wolch 1987: Snow and Anderson 1987: Lovell 1997). This thesis inadvertently is likewise subsumed as it deals specifically with deinstitutionalised schizophrenics found at various drop-in centres.

## **Methodology**

To understand how schizophrenics live is an important endeavour for anthropology because it shows the familiarity in the unfathomableness of the other. Psychosis. craziness and/or madness are not something we see in ourselves. but rather something we readily cross the street to avoid. It is however. anyone's potential. The situation of schizophrenics is also one of our making etched out with our social. cultural and political tools.

Schizophrenia is one form of madness whose exploration is as much one of revealing otherness as it is one of reflecting self.

Madness because it marginalises, also silences. In this regard anthropology is able to provide a voice for people who are rarely heard. Anthropology can also legitimise and authenticate the voice of madness and allows for insight into the experiences of those who, because of their disease, may not have that insight themselves.

Primarily concerned only with those living outside of asylums, the undertaking for this thesis was limited in scope. Madness maintained its foreignness throughout the field work and as such I was never entirely submersed in the field, much less in danger of "going native." Some of my informants I came to know as friends but it was not possible for me to gain an empathic or tacit understanding of schizophrenia as madness. This thesis then, relies on a different way of "being in the field" and of gathering information. This work is based on almost two years of fieldwork in a variety of drop-in centres and missions where general observations on a diversity of users and specific observations on schizophrenics were made. Hundreds of hours making observation were broken into short periods of serving coffee, breakfasts and lunches in drop-ins. Occasionally I "hung out" at missions where people were able to spend the night and either made general observations, conducted interviews or sat in on sessions with caregivers assessing individual users. For the purpose of this work, the fieldwork presented here is limited to five such places where workers and schizophrenic users of the facilities were interviewed. I also developed relationships with the schizophrenics presented in this thesis. For some this meant simply having coffee outside of the centres while not conducting an interview. For some it meant nights out at bars, sharing drinks and still for others, this encompassed visiting them at home to share a meal.

Missions (places offering a bed for the night) and residences (similar to dormitories) were regularly staffed and did not seem to need the occasional volunteer. Hanging out in these spaces was conspicuous. Although I attempted to hang out in two

such places. this was mainly to get a feel for the space. These places afforded great opportunities for interviews. There were always a lot of people there and staff were eager to help out in selecting prospective interviewees. In addition I was able to chat with staffs. Once, while out making the rounds with an outreach programme's social worker I spent an evening sitting in on consultations between the users and the social worker.

The bulk of my research occurred during the day and typically involved arriving at one centre at seven o'clock in the morning to prepare peanut butter sandwiches and coffee. For the hour before the doors opened I was able to chat informally with staff. There was always a line up and based on a system of first-come, first-served, it took about an hour before the sandwiches were gone. I was able to use this time only for the briefest small talk. Serving breakfast mainly allowed me time to make observations. Between breakfast and lunch, I usually chatted with staff, ran small errands or spoke with the users. Because of space, I was unable to conduct interviews at this centre so my time there was used mainly to set up appointments for interviews later on in the day. My presence at this drop-in and the fact that I was working helping to serve the meals made me visible and approachable. Because I would be seeing the same people in different places throughout the day this sort of visibility and familiarity was essential.

After helping to clean up before this drop-in closed at one, I would move on to another centre a few blocks away. I took a less active role here. Usually I would spend about two hours drinking tea and talking with the staff and users. I tried to be present for part of dinner at four o'clock. Before that time I was able to visit other centres to check up on a few, specific individuals. Often during this time I had interviews to conduct. Initially I interviewed schizophrenic informants in a room at the second drop-in but I soon adopted a less formal space in a coffee shop. As part of the requirements of the larger research project, informants not part of the regular staffs (i.e. users) were given a \$20.<sup>00</sup> honorarium.

Staff could be interviewed before or during work ("on the go"), over a breakfast or while we set things up for the day. Occasionally, office hours were set aside for a more formal interview. Sometimes we conducted the interview over an after work beer.

For the interviews, it was important to me that the interviewee be relaxed and to this end I embraced an informal interview style in an informal setting. Questions during the interviews were open-ended. In the course of setting up the interview, I had clarified that I was neither a psychiatrist nor a psychologist.

Typical first interview questions started out very simply. Although the schizophrenic informants had been verified by staff as schizophrenic, because I wanted the informant to talk about his/her illness, the first question was usually about why they come the centre and what they do there. If specific diseases were mentioned, I tried to have the informant explain what they were, how the diagnosis came about and what the treatment involved. Similarly for the workers, I asked such things as what they thought schizophrenia was, how they distinguished schizophrenics, how effective they thought treatment was and why they were doing the work they were doing.

Of course a lot of information was gathered outside of an interviews. As I got to know the informants better, regular conversations over the breakfast counter and throughout my time at the centres were increasingly meaningful. Eventually I started to get invited out to clubs and bars and sometimes over to apartments and rooms just to chat. One way in which I knew I was succeeding in becoming an "insider" was that panhandlers recognised me and stopped asking for money. (Preferring instead to talk for a few minutes.)

Urban anthropology poses several interesting situations. This research reveals huge aspects of my home city to which many that live here are utterly oblivious. It also presents a need to come to terms with one's own sense of taking things for granted. For me, Montreal is an extremely well connected city with its transportation network putting everything easily at hand. I have never had to rely on a hospital for my own health. Many informants however spoke of harrowing experiences with the police, the hospitals and other institutions

as well as having difficulties moving through the city. As much as this was a study at home of the unfamiliar, schizophrenia as other, it was also the reconfiguration of the familiar as unfamiliar.

Methodologically, urban anthropology in one's home city also allowed me an unexpectedly different exploration of the informants. As much as I seemed to fit in as a colleague among most of the workers, users have become an inescapable part of my life. They are still regulars at bars and all night coffee shops I frequent. I still meet many on the bus. One drop-in centre user is a street worker in my neighbourhood and is always eager to keep me up to date. The research did not keep regular hours and in many ways is still ongoing.

Throughout this work, informants are generally divided into two groups, care givers and users. In drop-in centres, and missions this distinction is less stable than it appears. Not all the users were schizophrenic or even mentally ill. Several had drug problems; some were prostitutes; all were poor. Although I focussed on schizophrenics in these places, the other users also illuminated for me many things about these places and told stories about the schizophrenics. In these ways non-schizophrenic users were also informants about schizophrenia. Among the staffs, it was not uncommon to find users who were working at the centres to augment their social assistance as part of a programme designed to provide them with extra money. Occasionally there would be a caregiver whose own life afforded him a rare empathy with the users. Some caregivers had pasts involving drug problems, prostitution and/or homelessness. One caregiver that stands out was epileptic. I remember him retelling a story of how he was treated while having a seizure in a subway station. Security and the police thought he was on drugs and his medical care was inadequate. Such stories also seemed to collaborate those of the users. Interviews with the variety of informants often overlapped on topics and subjects. As informants spoke about themselves and others they not only helped to complete the stories of others but also inadvertently revealed their relationships with other informants.

Diagnoses of schizophrenia were either confirmed by the informant or by staff and permission to conduct the interviews was given by the informant although staff initiated any approach to them. In this way, staff ensured that the informant was relaxed and not threatened by the interview. Although this was to ensure my safety as the interviewer as well as the well being of the informant, it also meant that selection of the interviewees was limited (for the most part) to lucid, non-psychotic schizophrenics.

In any case, information in this thesis is based on formal and informal interviews with ten schizophrenic informants, six centre workers and observations made while serving meals, "hanging out" in the centres and one night out with an outreach team that toured the city's network of centres and missions. The internet was also a rich source of data.

Most of the informants presented here provided more than one interview, which enabled me to go over unclear parts of the first interview. Usually the informant had had an opportunity to read the transcripts of the first interview and offered clarifications of their own. Workers particularly volunteered elaborations of what they had said previously. Analysing narratives and using life histories to reveal the storyteller were central to this work.

It is important for the reader to know that this thesis is not concerned with what I term 'institutional truth,' that is the truth about informants as preserved in records such as those of the police, the courts, the hospital or any other institution which could be used to chronologically map out events in a person's life. As far as the schizophrenic informants are concerned, this thesis relies on the retelling of their stories as they retell them, as truth as they understand it to be.

Most schizophrenic respondents in this thesis used a narrative style that presented difficulties pertaining to what we often take for granted in story-telling and narration, namely a sense of continuity and cogency. Generally, we "take for granted that every narrative takes place within an uncriticized temporal framework, within a time that

corresponds to the ordinary representations of time as a linear succession of instants” (Ricoeur, 1981: 166).

States of psychosis are not easily recounted rationally. During interviews however, few of the informants were in a psychotic state. Although many informants were clear and cogent when speaking about the present, their sense of past often lacked a sense of chronology. Not only were events out of order, but the duration of the events themselves were often out of sync with the gravity of the event. Bureaucracy alone would make being arrested, diagnosed and treated in one day unfeasible. The informant often seemed to be “breezing over” these incidents to cover up a sense of shame at being arrested or even diagnosed with a mental illness. The integrity of a time line makes a story easier to follow; however, a distorted time line does not necessarily undermine the facts of the story. The facts of an arrest, a diagnosis and a treatment, even if they are not necessarily in that order, remain essential sites for enquiry and understanding.

As alluded to in the opening quote by Eddie, the difficulty of voice, text and narration lies in their degree of (in)commensurability. Not only will it be difficult to interpret and understand much of the schizophrenics’ narrations, but also as an anthropologist, the same problems may occur with unfamiliar styles in difficult professional and academic texts relating to psychiatry and psychology particularly. However, in searching for meaning in what is said, we must not forget what isn’t said. Remember Foucault: there is no binary opposition between what is said and what isn’t said. Inextricable from the different ways of saying and not saying things, are the strategies that underlie and permeate discourses (Foucault, 1978: 27). Stigmatisation of mental illness, abuse of the system by the mentally ill and abuse or harassment of the mentally ill by the police and caregivers are all part of these strategic silences.

Storytelling will be seen as story-making and understood as an integral part of forging an identity. Although this will be true for all informants, schizophrenics’ narrations, often disjointed and lacking a sense of continuous time, allow not only the story to forge an

identity, but the process of narration as well will create a space for alterity not only between individuals, but between ways of being individual, specifically noncontinuous and without temporal limits. How the professional texts are worked into narrations by the adoption of jargon is an indicator of the degree to which the schizophrenic accepts their diagnosis while also displaying a certain amount of savvy they possess regarding their situation.

Identity will also be understood by reference to general texts on schizophrenia as well as to narrations on schizophrenia in general and specific schizophrenics by doctors and other care givers.

Schizophrenic story-telling-making relies heavily on a nonchronological dimension of narration in which scattered events are construed into significant wholes by the plot (Ricoeur, 1981: 174). Schizophrenia is its own plot and the experiences of it are the scattered events construed into the whole. Ricoeur contrasts this to the episodic dimension (chronological) which "characterizes the story as made out of events" (*ibid.*). In either case, inadequacies caused by constructing a whole when scattered events may be missing or misplaced indicate problems with the narrative that alone reveal rupture, shame, confusion and/or failure. Such upsets are indicative of the inconsistencies of current understandings of schizophrenia and the ramifications of deinstitutionalisation's shortcomings.

Returning to Ricoeur, I wish to adopt his notion that the plot is "the intelligible whole that governs a succession of events in a story" (Ricoeur, 1981: 167) because I believe that my informants used schizophrenia as their plot in a way that not only made sense out of the events of their story, but guides, and explains paths of their lives towards a climax. The events that mark schizophrenia are relatively short in duration, the psychotic episode, diagnosis, treatment, etc., yet as events they chart schizophrenia as a plot. If a story is indeed "made out of events to the extent that the plot makes events into a story" (*ibid.*), then these discrete events tell not only the story of schizophrenia, but as a story, illuminate the process by which events are reconfigured, told and read as a chronic illness -- a situation (Estroff, 1993: 251). Schizophrenic life histories reveal more sharply than other life



histories the past and the future, or at least a relatively limited array of alternatives to the perpetuation of their current (chronic) situation.

For a variety of reasons, schizophrenia presents the academic with a challenging topic and in several ways, a topic in need of its own epistemological tools.

### Theoretically

There are five main veins of thought that have informed the theory behind this paper and in an effort to develop that theory I begin with them.

The first line of thought relies on the assumption that schizophrenia is a biological brain disorder. As a disease, schizophrenia is indiscriminate meaning that any *Homo sapiens* is susceptible to the disease. Schizophrenia may be anyone's biological potential. However, the symptoms of the disease are manifest in a particular cultural *milieu*. How the person acts out (insisting on crossing on red lights for example) or the voices they hear (God's voice), are culturally and not biologically significant.

George Devereux notes that it is the differentiation, individualisation, plasticity and variability of behaviour that provides humans with the unique ability to create distinctive cultures that is inherent in our biological potential (Devereux, 1980: 289). As a biological brain dysfunction however, schizophrenia is equally part of our biological potential and the natural variability between individuals. As a set of particular behaviours schizophrenia is also implicated in that unique ability of humans to create distinctive cultures. Current treatments, aiming to control schizophrenic episodes, suppress symptoms and ultimately cure and eradicate the disease, are in some ways attacks on culture. Biology is denied a cultural expression. The assessment of schizophrenia as dysfunction then becomes itself a partial realisation of cultural dysfunction: an inability to accept certain biological deviations culturally expressed. How a society treats schizophrenics is a window into a range of other social problems so far as the stigmatisation and marginalisation of schizophrenics is a denial of society's own dysfunction.

Similarly, by being labelled, singled out for special treatment and stigmatised, people with schizophrenia come to represent a type of person, namely a schizophrenic. They then come to stand in contrast to 'ordinary' people (*normals*) and their self is merged with disease. In this sense being schizophrenic is a social role and not necessarily the observation of a range of symptoms indicating schizophrenia and culminating in a diagnosis.

Barham illuminates my third theoretical perspective as he relates a story about a researcher interviewing an informant with a severe mental illness. During one interview the informant asked, "Why don't you ever ask me what I do to help myself?" The researcher, reflecting on this, wrote:

What she and others suggest is that the person as an active agent interacts with mental disorder in a crucial way that influences the course of that disorder. Thus, in contrast to some models of mental illness ... my hypothesis is that the role of the person in mental disorder is not peripheral, merely as a passive victim of the disease to be fixed by medicine (Strauss in Barham, 1997: 95).

The point brought out in this reflection that the diagnosed person manages the course of their illness refers to the agency of the schizophrenics. It is also one aspect of the eroding authenticity of a purely medically managed regime and cure. The withdrawal of psychiatrists from front-line care, as explored later, is part of this erosion.

Fourthly, there is another point that underlies the fallacy of a purely medical treatment, the intrusion of public policy into health care. Most obviously this is realised in the push to deinstitutionalise as a means to reduce health care expenditures. More generally however, it is what Foucault saw as the "deeply rooted convergence between *political ideology* and those of *medical technology*" (Foucault, 1975: 38). In this thesis, this convergence means the deployment of technical fixes, such as anti-schizophrenic drugs, to assuage a number of societal ills and suppress a variety of "delinquent" behaviours.

Finally, I believe that the fundamental understanding of what it is to be schizophrenic lies not with the experience of psychosis. Instead it is in the persistence of a variety factors, such as the diagnostic label, a pharmaceutical regiment and health care's

revolving door that ultimately makes the experience of relative wellness (non-psychosis) part of the continuity of the disease. It is the inevitability of relapse and psychosis that makes schizophrenic chronic in nature and links the life one lives as a schizophrenic with the disease of schizophrenia itself.

My main theory begins with the understanding that the diagnosis and course of schizophrenia is neither a neutral nor an inevitable process in which the schizophrenic is created. Moreover, the treatment is one less driven by effective biological treatments than political ideology, technology and personal motives. Fundamentally it is the process through which the schizophrenic is diagnosed – labelled – and the means of his/her treatment that defines what schizophrenia is and hence what it is to be schizophrenic.

#### **About the Written Work**

Used in this thesis are many words in need of definitions. Although these definitions are given throughout the thesis, many are elaborated late in the work after the terms themselves have already been introduced. I am therefore including a short list of words and brief definitions as they pertain to this thesis.

Schizophrenia is the diagnosis of a particular mental disorder. The schizophrenic is the person diagnosed with this disorder. More than a clinical entity, being schizophrenic intimates the endurance of the mental illness and the persistence of a situation. Although this situation is marked most obviously by continued treatment, it is also one closely linked to a variety of social issues such as unemployment and homelessness.

Situations, side effects and stereotypes create a negative impression of what schizophrenia is. This impression is the stigma associated with schizophrenia. It is this stigma rather than the diagnosis against which the "normal" is contrasted. "Normal" is a term used in stigma theory and should not be confused with "non-schizophrenic." Because a large part of this research took place in drop-in centres and other community-based centres, "normals" have to be identified as those outside of a situation that would require reliance on such services and not just those without schizophrenia.

Chronicity anticipates the potential for relapse and the persistence of some symptoms associated with schizophrenia. The chronic nature of schizophrenia is one of the ways in which schizophrenia as a situation is perpetuated.

Florid symptoms are symptoms synonymous with positive symptoms, which are delusions and hallucinations. Florid however, will also be used to imply that the symptoms are severe and that the schizophrenic is unable to hide, ignore or suppress them. Florid symptoms reveal schizophrenia in as much as their presence may validate the notion of chronicity.

Deinstitutionalisation is the closing of state, psychiatric hospitals (asylums) in which people with mental disorders were formally maintained. It is also the process through which care for the formally institutionalised is shifted to community-based centres as a means of reintegrating them into the community.

Functionality is often used in this thesis and is a measure of schizophrenics' abilities to cope with and function in society. As a scale it covers a range of possibilities. In this paper it should generally be understood as marginally functional and assesses schizophrenics as non-threatening, stable (their symptoms are not deteriorating) and as able to keep up with their own treatment regimes. Functionality means less intervention is necessary. This in turn is part of what makes deinstitutionalisation possible.

One of the challenges for me in producing this written work was to make it accessible. Throughout the research, transcripts of interviews were given to all the informants. Only one of the schizophrenic informants, Shelly, returned to follow-up interviews with the transcript of the previous interview. Marked in red, they had spelling corrections, clarifications in the margins and questions throughout. I kept Shelly in mind throughout the writing of this thesis and it is what it is (reads like it does) in large part because she is one of my audiences.

The rest of this thesis is divided into nine chapters and a brief conclusion. The first to follow this one sets the tone for this thesis by using a story placed on the internet by a

schizophrenic in Ontario detailing his life and struggle with the disease. The third chapter provides an overview of the history of deinstitutionalisation beginning with institutionalisation. The fourth chapter introduces schizophrenia as a psychiatric mental disorder followed by how this disorder may be overlaid onto the subjective life experiences of schizophrenics as presented in the fifth chapter. Chapter six describes the physical spaces in which my fieldwork took place. The seventh chapter explores, through some life histories, what it is to be schizophrenic particularly after deinstitutionalisation. Chapter eight is another life history but one that draws light on the similarity between psychiatric and social conformity. Chapter nine draws out the tension between adhering to treatment and denying its efficacy or accuracy. Finally, the chapter preceding the conclusion explores some ways in which schizophrenia proves its utility and questions the validity of a variety of social forces that regulate the role of the schizophrenic.

## Chapter 2 - Chovil's Story

Schizophrenia is not a terminal disease, but the poor quality of life it affords the majority of schizophrenics helps to explain strategies schizophrenics employ as they narrate their lives and distinguish between self and illness. Schizophrenia is a disease that exacts a price financially, socially and personally. In strictly financial terms, schizophrenia strains resources and budgets. Lost productivity has financial ramifications as well. Any diagnosis of a mental illness is likely to have an associated stigma. In the case of schizophrenia, such a stigma may involve associations like those of homelessness, unemployment and poverty that are not linked to the diagnosis itself. How schizophrenics employ a range of strategies to manipulate that stigma and their situation reveals the degree to which the disease has circumscribed their identity and impoverished their sense of self. How informants' story making uses time and adopts the professional terminology of their diagnosis all reveal how, and with what tools their identities are forged.

The following is a presentation of one story that while providing examples of the clinical symptoms of schizophrenia also shows how these interfere with and overwhelm the life and goals of the individual. The symptoms and phases of schizophrenia and relapse are drawn out and spoken of in terms of dropping out of school, job loss, estrangement from family and friends and social alienation.

This story is taken from Mr. Chovil's web site with permission. In e-mail correspondences with Mr. Chovil, he wrote, "You can use whatever you find useful. I feel that my experience is only useful if people can learn from it so that others won't repeat it." None the less, because it is a story taken from the internet, it should not be seen as representing my own data but rather as an articulate narrative that I am using to set the tone for this thesis. More than anything else it may prove revelatory for the reader who has no experience of schizophrenia.

From Mr. Chovil's current perspective, he is able to understand his disease and diagnosis. His story is useful here in illustrating the phases of schizophrenia, their inevitability (especially relapse given his refusal to maintain treatment) and how the part of his life presented here was a schizophrenic experience. That is to say, that his actions made sense to him at the time, are expressions of him as an individual and can find no explanation *per se* in his clinical diagnosis.

Asked to elaborate one point in his story, Mr. Chovil noted the following as a bit of a caveat. "I guess my story is only as good as my memory, and there are some things I leave out because they are either incriminating, or very personal. To condense 20 years onto a few pages means a lot of detail gets left out as well."

Schizophrenia can come on rather suddenly around age 18 in men and 25 in women or it can have an insidious, meaning gradual onset. My schizophrenia seemed to start when I was about 17-18 although I was not a well adjusted teenager before that. I developed my first major romantic relationship at 17 which gradually deteriorated over the next four years. With an insidious onset you gradually lose your relationships with friends, family and lovers, as your symptoms increase and you end up quite alone. My mother says now that she noticed a change around 18, that I lost all my ambition to succeed. When I was sixteen I scored in the top three percentile in a province wide mathematics contest, and my favorite subjects were math and physics. By the time I was eighteen I had lost interest in school and only applied to university because my father was so insistent I go. I was quite strange from 18-25 at high school and university and thought I needed psychological therapy along the lines of Gestalt therapy or Rolfing. I was a very rebellious teenager who experienced a lot of emotional turmoil. One significant indication of schizophrenia was my inability to plan my future. I took courses that sounded interesting, smoked a lot of marijuana and drank too much at parties. I was notably incapable of and uninterested in long term romantic relationships and in fact was very anxious in any kind of social situation. I doubt that any psychiatrist would have been able to diagnose schizophrenia at that point though. I graduated with an Hon B.Sc. from Trent University with a double major in biology and anthropology. I applied to one graduate school at the last minute as I realized that my degree was not a career and was accepted.

At graduate school in Nova Scotia in 1978 I kept going to the university clinic about my physical health, afraid that my health was going to fall apart, that I had picked up a form of syphilis that couldn't be detected by standard lab tests, etc. I was referred to a psychiatrist and before long I was hospitalized for a couple of weeks. What started as having an analyst like Woody Allen became an involuntary hospitalization. I had some delusions that Jim Jones, who was responsible for 500 people committing suicide en masse, was trying to force me to commit suicide but I never told anyone. I was getting pretty confused though. Unfortunately no one mentioned schizophrenia to me or my father, who is a physician, and I thought I had

just had some sort of nervous breakdown. I saw someone after I was discharged about once a month for a few months. I remember taking Chlorpromazine before I was hospitalized which I didn't like and some Stellazine after I was discharged. My father encouraged me to take it but I was scared of it and I only took it for a little while. The medication seemed to cause my delusions and I believed that for many years.

My father convinced me to try and finish my year even though I wanted to drop out. It was a very miserable year for me. Some courses went unfinished and I was kicked out of graduate school. I worked for a summer in Toronto, the fall in London, and then I headed out west to Vancouver Island. I knew someone there in a small pulp mill town called Crofton but he moved up island and I rented an apartment in the strip joint tavern, alone again.

As I relapsed I had mostly delusions and paranoia. I thought the CIA was after me for awhile after I wrote a letter to the editor of Science magazine about how the US military was using dioxin as a weapon in Vietnam. My delusions had faded for the previous summer but they had never completely disappeared. That is to say I believed some pretty strange things. In Halifax I thought I had discovered the cause of World War Two. The influenza epidemic of 1918 changed peoples' nervous systems so the cause of the war was a neurovirus. I thought my law professor in Halifax was very well connected with influential people in world politics and was telling people about my theory. Various important people were coming from Europe to meet the man who discovered the cause of World War 2. So for example someone might come up to me in Crofton and talk about mopeds and I would think this man was the president of Motobecane, the world's largest manufacturer of mopeds. People seemed to know me before I introduced myself, and the local townspeople seemed to be laughing at me. I remember once the political cartoon in the local paper seemed to be about me and people who picked me up hitchhiking seemed to know who I was.

In the spring of 1980 I left Crofton forced out by the townspeople who demanded I get a job. I took the bus with no destination in mind until I ran out of money. From then on I usually hitchhiked, mostly through Chucka and B.C. quitting a job with my first pay check because I found working with people so difficult. They were playing games with me and making fun of me. I would then hitchhike somewhere else. I thought I was being followed by a WW2 veteran everywhere I went who wanted me to shape up by working in construction like he did after the war. I kept trying to escape him but he had friends everywhere. I slept in city parks, by the side of the road and in single men's hostels. I was homeless and often penniless. I remember once in Calgary staying at the single men's hostel and not getting to eat very much for several weeks, becoming quite weak. I couldn't work because I had dioxin poisoning and this was affecting my cortical hormone balance making work too stressful. Tibetan Buddhist lamas were reading my mind everywhere I went in Calgary, respectful and curious, because I had caused the Mt. St. Helen's eruption for them earlier that year through tantric meditation.

I don't think I quite understood or believed what was happening to me, but I was determined not to admit defeat and return to my parents house. It seemed like I had powerful friends who wanted me to pull myself up by my bootstraps. Only two years earlier I had been in graduate school, with a new friend, David Rae, discussing world politics while watching the CBC news at a local bar. David's brother, Bob Rae, later became the Premier of Ontario. Come late fall I was in Victoria, driven south by the approaching winter. There I was somehow able to pay rent and I stayed there for four years. I



started studying Tibetan Buddhism and took refuge in the lama who lived there. Tashi Namgyal. I thought he was capable of all kinds of supernatural powers of the mind like telepathy and telekinesis. It is a tremendous invasion of privacy to have someone reading your mind all the time uninvited. I believed he was controlling my dreams while I slept as well. He said to me in his broken English. "you special" and I thought that meant I had a lot of natural ability to be a very powerful tantric like him. He was the equivalent of a graduate teacher in the Tibetan monastic system.

I had caused the Mt. St. Helen's eruption with his guidance through tantric meditation. I had bad karma so I wasn't given control or access to my power but by causing Mt. St. Helen's to erupt the Tibetans were taking pressure off the California continental plates. We saved San Francisco.

I had gone to several family physicians about my physical problems of which dioxin poisoning seemed to be the cause and I thought it was also causing my adjustment problems but the family doctors never realised what was happening to me and I stopped going to them and instead thought this Tibetan Buddhist lama would be able to help me, because I did realize that something was wrong.

I was losing contact with reality gradually and stayed in abject poverty and I was miserable. I remember I bought a WW 2 rifle to please the WW 2 veteran and I would sit in my basement room with the barrel in my mouth and wonder if I should pull the trigger. I started to think Tashi Namgyal was evil because he was celibate and I got messages from Beatle songs which I thought were from the Maharishi Mahesh Yogi to run away and that's what I did. I thought there was a war going on between two groups, both with supernatural powers, that would decide the fate of humanity. I called one the Sexuials and one the Antisexuials, because these powers came from sexuality. I forget some of my life out west. I do remember being very miserable and very alone, identifying with Milarepa who is a Tibetan saint of sorts. The Tantric tradition, which is very interesting, has its roots in India. In the ninth century these supernormal powers were close to becoming a part of society. Tibetan Buddhism incorporates a celibate tantricism in its teachings which has survived I think because it is also very religious. I was entranced by the erotic temples in India like Konarak and determined to become a tantric and help the world rediscover the supernormal powers of the mind in sexuality.

In Toronto I managed to get a job changing light bulbs at a large department store. I ran away twice, to England and Jamaica<sup>3</sup> expecting to be welcomed

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Asked where he got the money from to run away. Chovil responded:

The trip to England was financed by my father. He had given me 300 shares of Dome Petroleum because it was some sort of American tax loophole, and he was hoping I would start learning to play the stock market. They sat there for a considerable length of time because it was more of a loan than a gift. But when I thought people were trying to kill me, I desperately had to get somewhere safe so I sold them and bought my ticket to England. I had sold 100 shares to move back to Ontario from Victoria, and the last 200 to fly to England. Fortunately there was enough money to fly back as well, and then all that money was gone.

The trip to Jamaica was fairly cheap, \$400 return for two weeks or something like that. I was earning enough at my job to save that much. I didn't take any spending money for the trip though, since I again expected to find refuge with the Maharishi who would take care of me. I remember vaguely thinking I would become a teacher or something like that. I never expected to use the return half of my ticket but couldn't buy a one way. I

personally by the Maharishi. When a terrorist bomb blew up a plane over Lockerbie Scotland I thought it was an attempt on my life, which prompted me to fly immediately to the Maharishi in England but he wasn't there and I came back the same weekend. I saw a movie called "Oedipus Rex" directed by Pasolini and immediately flew to Jamaica expecting to meet the Maharishi. I was looking for Strawberry Fields mentioned in the Beatles song and there are two in Jamaica. It was a memorable trip. I ran out of money after one week and mostly learned the importance of money.

I was just a pawn in a secret war. I didn't have any friends, any lovers, and very little contact with my parents between 1980 and 1990. My parents had moved to the States while I was in Victoria and I never told anyone what was happening. I lived in a cockroach infested rooming house never even realizing that Diazinon will eliminate cockroaches. I had a strong sense of mission to help humanity instead of myself and in my poverty I believed the cause of suffering in the world was overpopulation. My solution was to hybridize the AIDS virus with the common cold and eliminate 3 - 4 billion people.

I got a lot of messages from favorite Rock and Roll songs, from movies, cartoons and library books. The library was my special friend who could show me what I needed to know by having me open and read exactly the information I was looking for. Someone was leading me to the books I needed and that was too much for humans to be capable of. I started to believe I was in contact with aliens from outer space. At first there were two kinds. I learned humanity was going to become extinct from a nuclear holocaust that would break up the continental plates. The oceans would evaporate with all the molten lava and I was going to live in a box out in space with a woman the aliens had been breeding since life started on this planet. She had dark blue skin like the Hindu god Krishna and we were going to have children who would be turquoise in colour. We were going to be the only survivors of Armageddon and we would propagate the species. Only girls would be born as identical twins and they would be able to impregnate each other from a single drop on their funny long noses. I would be the last surviving male although I would only live a thousand years. I believed that to be my destiny completely and got a lot of messages everywhere I went. I heard voices several times but mostly I experienced telepathy. I had what are called "ideas of reference" where things are thought to have a particular meaning just for you. For example, a license plate on the street could be an important and appropriate message for me from the aliens. By the end my fate had changed a bit. I was going to become an alien and have eternal life and be capable of time travel and my companion was going to be a part time anthropology professor at the University of Toronto. Sexuality was as important as intelligence to the aliens and they had evolved beyond the use of machinery to doing everything with their mind. I thought they were turning on my nervous system with experiences of pain so that every neuron was active, so that I would be able to experience greater pleasure as an alien. I asked them once if a machine might not make the process less painful and I remember them laughing, saying "Machines... Ian, we don't have any machines."

My delusions changed as the aliens instructed me on the real nature of reality. Three things happened as my contact with reality became very

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didn't eat the last few days in Jamaica not having any money at all, and waited two days at the airport to catch the plane back.

tenuous. I got in trouble with the law. I became alcoholic, and I lost my job. One night after convincing the aliens to transfer my mind to another body I got mad at the aliens, and started breaking windows in the rooming house I was living in. The police came, subdued me and I spent a couple of nights in jail. The judge realized I was a psychiatric case because I carried a pocket-knife to defend myself against homosexuals. The world's most powerful man was a homosexual and he was trying to make me a homosexual. By then the Maharishi was my second worst enemy. I believed they both knew about the end of the world and my destiny with the aliens and they wanted to take my place. I didn't mention that in court though.

Nobody asked why I did what I did. I got three years probation with the condition that I see a psychiatrist for those three years. Psychiatrists are only human though, while I was almost alien and they wouldn't have understood what was happening so I never told them anything. I went to my appointments to stay out of jail.

Jail was such a shock to me. I was so mad at the aliens after that experience I tried to force them to give me a new body by killing the body I was in. I bought several bottles of vodka and guzzled them like water until I passed out knowing that people overdose and die from alcohol. I got pneumonia but lived and decided that the aliens wouldn't let me die, only experience pain until it was time for me to go.

Although I didn't drink anything for awhile I eventually started to drink and heavily because I could afford it. You need \$11 an hour to become an alcoholic. Originally I drank for the hops which I thought were medication for celibacy. My behaviour became more and more bizarre and I was fired from my job. I went from unemployment insurance to Welfare, brewing my own beer in plastic pails and eating in soup kitchens. I thought I was going to become an alien when I turned 37 because I saw a book written by the ancient seer Nostradamus entitled 3791. I thought that since he could see the future he would realize I was not capable of understanding the book and that all I would need to know could be explained in the title. I turned 37 in 1991 a year after moving to Guelph but I'm still here unfortunately.

I experienced many extreme emotions when I was psychotic with positive symptoms. In fact it's a wonder I didn't come into contact with the police before I did. I can say that I never harmed anyone but I realize I came very close, although I experienced more fear than anything else. I am by nature a gentle person who has never fought with anyone. Family members I have met in Guelph have usually had some experience of verbal abuse or physical assault from their ill relative before they were treated. I remember I thought I was dying from celibacy and I hated women for a couple years even though I went through adolescence with only feminist friends and was convinced women were the superior sex. Schizophrenia can force you to feel and do things that are not in character for you. Dr. E Fuller Torrey says violence in schizophrenia is predicted by three factors.

1. a previous history of violence.
2. substance abuse.
3. not on medication

I would destroy my own possessions first like my guitar without having much choice. I shied away from people. I remember sitting on the ledge of a window on the sixth floor wanting to jump but knowing that the aliens would have an open truck loaded with mattresses come by just as I jumped and when I actually saw such a truck weeks later it only confirmed my conclusions.

I didn't win the lottery though after I lost my job and the people in my rooming house started mainlining heroin in the living room. I was desperately poor by that point expecting to become homeless and sleep on a hot air vent and I couldn't believe that was necessary in becoming an alien. I was experiencing quite a few blackouts from the drinking I was doing and getting scared of alcohol. I kept waking up in strange places. One fellow in the rooming house had attacked me with a chain such that I needed stitches above my eye. I was too disorganized and too poor to find another place to live. My mind seemed to be falling apart into the left brain, me, and a right brain I hardly knew who was in tremendous pain and very demanding, and a dinosaur or core brain, very powerful and very angry at me. I agreed to go to the Homewood Health Centre in Guelph to be treated for alcoholism. Going into hospital was the easy way to get out of a situation that was very frightening. That was at the end of my three year probationary period.

As I sobered up my delusions faded a lot and I realized I had no concrete proof of aliens or my imaginary wife. I also realized I couldn't put my faith in aliens to take care of me. I moved into a basement room in Guelph and started a maintenance dose of antipsychotics. The year was 1990. It took several years to completely believe and understand that I had schizophrenia though. I was sure I had been misdiagnosed, and I would much rather have had bipolar disorder so I could compare myself to various famous people. I wanted to go off medication but the psychiatrists were very firm about that. Medication didn't seem to have any effect so there was no reason not to take it. It kept my psychiatrist happy.

I was very depressed for several years and very lethargic. I didn't accomplish very much and was quite anxious. I lived in basement rooms, had no friends and little contact with anyone. At that time I was seeing a psychiatrist at the Community Mental Health Clinic once a month or so. I don't think my period of depression could have been avoided. Antidepressants didn't help which suggests I didn't have an actual depression. I was very anxious having nothing to do and no one to do it with and had very low self esteem. My mood eventually improved a bit and I made a couple of friends and became more active. I started to do a little volunteer work and I eventually met Rosemary and courted her. I started to work for some extra cash, delivering flyers and then the local newspaper. Rosemary and I moved into the apartment building where I delivered newspapers. We shared a two bedroom apartment for 16 months until the Provincial government made that too expensive<sup>†</sup>.

The quality of my life has been improving a little each year for the last eight years so I can't complain too much but every once in awhile I really feel the losses I am enduring. Life is a series of opportunities as you grow older, and I missed all of those opportunities. I wonder about my future alone. Living on a limited budget could make anyone miserable. Being celibate is a great loss many people don't mention to anyone. I will never get to experience what a lot of people take for granted. I may never own a car. I may never marry. I may never have a vacation again, let alone full time employment. It is only in the past couple of years that I can say that I have been able to accomplish anything productive. Before that I was pretty unhappy and didn't

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<sup>†</sup> Elsewhere on his site, Mr. Chovil says that changes to the Ontario government's regulations on social assistance reduced Mr. Chovil's and his girlfriend's benefits by \$400 a month because they were living together.

feel very good about myself.

My friend Susan says there are two kinds of people. You get on a plane that is supposed to go to Hawaii and instead the plane lands in Siberia. Susan prefers to use Arizona as the alternate destination. You can either learn to enjoy Siberia or forever feel bitter that you didn't land in Hawaii. Lately Siberia has been fairly pleasant. My life does seem a bit "empty" compared to ordinary peoples lives. I also have a lot of unpleasant memories in which I've done things I now regret. It's difficult to know how much I'm responsible for and how much schizophrenia is responsible for. I think it's important for me to focus on enjoying life as much as I can and not dwell on the past.

I went to Schizophrenia 96 a couple of years ago, sponsored by Eli Lilly. I was mistakenly booked at the hotel as Dr. Chovil and the next day at the conference in my sports coat and dress shirt I was just another psychiatrist and it felt pretty neat. This was the life I should have had. But the first keynote address by Dr. Weinberger, world-renowned researcher in schizophrenia, compared finding the cause of schizophrenia to finding the cause of the TWA flight explosion that was in the news at that time. There was no evidence that it was a bomb. Finding out what happened when all you have are the twisted pieces of metal scattered along the ocean floor was causing difficulties. Over the three day conference I became very depressed realizing how appropriate that image was for me. I could empathise with the psychiatrists who were looking at their patient in front of them and asking themselves "why doesn't this person have the same lifestyle that I enjoy?"

Mr. Chovil, from the perspective of a schizophrenic in remission is able to interpret the events of his life in light of his diagnosis. Nonetheless, this rearward evaluation is unable to account for a cause of his schizophrenia. However, it is clear from his description that the cause of his schizophrenia occurred long before his diagnosis was to be made: symptoms began to appear around the age of 18 when his mother noticed a change and he himself experienced unusual behaviour. As he tells his story, it is easy to see how his unusual behaviour could easily be associated with benign adolescent experiments with drugs, alcohol and a general complacency.

Chovil's psychotic phase seems to be centred between the ages of 18 to 25. Again though, the changes in school and the stresses of graduate school may have been used to explain his illness. He himself understood that he had had some sort of breakdown.

In any case, he was hospitalised, and treated. This seems to mark the beginning of period characterised by residual schizophrenic symptoms. Although the persistence of delusions makes the effectiveness of his treatment unclear, it seems that he did regain some level of functionality and recovery.

Poor understandings of his illness and the medications lead him to become non-compliant. Nonetheless, he continued to be functional. Even though he was kicked out of graduate school, he was well enough to work and began moving around. Social relationships were eroding however and he wound up alone.

The beginning of delusions and paranoia marks his relapse. This period also sees high mobility, unemployment, and homelessness as circumstances inextricable from his declining situation. Inevitably, Chovil relapsed into florid psychosis. He also became alcoholic.

Not before exploring a range of alternative explanations for his life and considering suicide did things begin to change for him. It took several years for him to understand what his diagnosis meant. Regular contact with a Community Mental Health Clinic, some volunteer work and an improved social network seem to have stabilised his situation and allowed his life to improve. By saying that his life is continuing to improve yet noting that he relies on an (inadequate) amount of social assistance, Chovil indicates that he still suffers some role impairment and that he is again in a residual phase.

Mr. Chovil feels some sense of loss; he also has a returning sense of normality. Policy changes, geared at those on social assistance, have disrupted Chovil's ability to forge certain relationships and implicate themselves as part of counter productive measures, in conflict with his treatment. While Mr. Chovil continues to improve the quality of his life, this involves a certain vigilance on his part and a resolve to stay on his medications and remain in contact with professionals.

### Chapter 3 - Historical Perspective

Insight into what it may be like to experience schizophrenia in a particular place cannot be dissociated from what it is like to experience schizophrenia at a particular time. In many ways, our current time of deinstitutionalisation appears to have brought us full circle through a period of institutionalisation to a time when again the mentally ill live in the community. This history of de/post-institutionalisation is one involving state intervention, the emergence of psychiatry and the medical gaze, the rise of pharmaceutical treatments and the decline of the welfare state amid shifting social and cultural expectations. This chapter explores that history as part of a process currently unfolding as deinstitutionalisation but also as one that established the ideological and epistemological space in which this unfolding is taking place.

Madness has existed before the clinical taxonomy of various disorders was established. How madness and madmen came to occupy a particular place in the iconography and thought begins, according to Foucault, at the end of the Middle Ages. Leprosy, now almost eradicated from the Western world, had seen the creation of institutions to which it could be confined. Inherent in this was an approach to dealing with disease that was predicated on the concept of exclusion. The outcast lepers would by the fifteenth century be replaced by "poor vagabonds, criminals and deranged minds" (Foucault, 1965: 7).

Prior to the establishment of asylums as fixed locales preferred for dealing with the "lunatic," there was the Renaissance image of "the Ship of Fools" (*ibid.*). Driving the mad out of cities and towns often was accomplished by handing them over to boatmen. Forced from place to place the mad were destined "to float endlessly through the waters of Europe" (Macdonald, 1998: 1). Making a prisoner of the passenger, the embarkation of the mad, would pave the way for their confinement by the mid-nineteenth century (Foucault, 1965). The "Great Confinement" (*ibid.*) of the seventeenth century was not only a rapid

and extensive confinement of the criminal, mad, poor and sick but was a new way of organising that confinement especially with regard to morality. In an era where work was an expression of worth and morality, madness was subsumed into the category of unemployed. Unlike the unemployed however, the mad would eventually be understood as unemployable. Treatments centred on vigorous work regimes were ineffective and it became evident that madness could not be cured by physical treatments alone. The unity of body and soul began to breakdown. Insanity was emerging as needing treatment different than that for poverty, unemployment and crime.

After the French Revolution, the freeing of prisoners inadvertently included the freeing of the insane. Although they were to be placed in special hospitals, these places did not yet exist so the insane were returned to their families. Unable to cope, the families sent them away again, back to the prisons. By now however, madness had its own category and was kept segregated from the criminals (*ibid.*).

Around the mid-1880s there seems to have been a recasting of Victorian thought into the discourse of progress. Just as biological and determinist interpretations of history, as well as doctrines of social evolution and selection were gaining in popularity, asylum inmates had increased in number while the percentage of those inmates judged to be curable was steadily declining. These two factors created a *milieu* in which the 'insane' were understood as the "madman", "grotesque" or "monstrous," requiring their institutionalisation to protect social morality. The asylum itself became less a place for cure and convalescence for the inmates and evolved instead into an instrument of their welfare (Barham, 1984: 15). The confinement of the insane in the nineteenth century was largely judicial decision intended to protect society. By this reasoning, asylums were indistinguishable from prisons. Inmates were often chained (Goodwin 1997: 7). It is in this situation of imprisonment, segregation and without treatment that the insane would be found by the likes of Pinel.



Disgust with the deteriorating condition in asylums and efforts to create alternative systems of treatment started the process of deinstitutionalisation. With the liberation of the lunatic from prisons came the effort to again provide effective treatment most noticeable with the treatment therapies of Pinel and Tuke. Bringing them out of the prisons, where they had been chained to walls, hidden and forgotten, also meant that the insane gained visibility. Particular to the new therapies was in fact a sort of scrutiny, surveillance, judgement and punishment. Responsibility to adhere to a moral code was thrust upon the lunatic. Madness, now seen as in contrast to rationality, could be overcome by rational treatments aimed at instilling morality and reason. Therapies involved living by example and dissuasion from deviance by threat of punishment. The example to be followed became a moral authority also gaining the ability to judge and punish. Specialisation of this role meant it increasingly fell under the responsibility of doctors. Gradually the role of the moral authority as noble and wise gave way to the scientific authority of doctors (Foucault, 1965, 1977).

The French Revolution with its organisation of doctors and the goal of a perfected social order also gave rise to the clinic which formed the modern setting for the practise of medicine and psychiatry. It is within this setting that the body becomes a site of knowledge and disease pathology becomes a biological phenomenon. Increasingly the patient is incidental to the disease and the doctor's perception of the disease gains supremacy (Foucault, 1977).

This was the history that Canada inherited. By the mid-1960's Canada had 11 asylums and over the next 60 years would gain nine more many with capacities of approximately 6000 beds (Goodwin 1997:6-7). Asylum beds reach their peak in Canada in 1962 with 55,000 beds (*ibid.*: 86).

### **Schizophrenia and Psychiatry**

Schizophrenia has close associations with social and historical progress, the ability of medicine to intervene in the brain and the rise of psychiatry. By the end of the nineteenth

century. major efforts were made to understand the world of disease and pathology. In this sense, the history of schizophrenia closely resembles the history of psychiatry which itself is inextricable from the scientism of the epoch. Couched in modernism and the rubric of "the civilised mind," psychiatry like modernity itself "is profoundly ideological and profoundly historical" (Comaroff, 1993: xi).

In the 1940's the accidental discovery of the utility of antihistamine drugs in reducing anxiety first in pre-surgical patients then on schizophrenics began the pharmacological treatment of schizophrenia. Generally, physical treatments for mental illness seemed to becoming more effective. Insulin treatments, transorbital lobotomies and electroconvulsive therapy brought psychiatric care closer to that of general medicine (Barham, 1997: 4). This combined with rising voluntary admissions and therapeutic inventiveness at the asylums fostered a favourable relationship between the asylum and general society by the 1950's (*ibid.*).

The 1950's saw the intersection of shifting, conceptualisations of madness that were more accommodating and tolerant with the confidence that a post-war era would usher in a better social order and the development of new anti-psychotic medications.

Antischizophrenic drugs have been effective in treating the symptoms of schizophrenia but have not shown advances in curing schizophrenia itself. Medications may be used to treat symptoms throughout the disease, but are more closely associated with suppressing symptoms involving psychosis. Technical advances in medicine as major enablers for deinstitutionalisation reveal the ease with which social problems may be dealt with (however ineffectively) pharmaceutically.

... drugs have certainly been a crucial instrument in the disposal of mental patients but the preoccupation with the 'technical fix' has obscured recognition of the web of moral and social relations in which the identities of ex-mental-patients are either made or broken. In the USA in particular, the celebration of drug treatment has resulted in the neglect of other forms of service provision. And most significantly, perhaps, the very need for drugs has been fuelled by the failure to tackle the social problems of former mental patients. [...] In these circumstances the prescription becomes a document in a political process (Scull in Barham, 1997: 88).

The movement to get people out of institutions and into the community had yet to anticipate the need for community-care beyond transitional services. Pressure to close asylums centred around the promise of new drug therapies and the critiques of asylums as making their own lunatics instead of the possibility of ongoing community-based care. Liberation from psychiatric conformity was made possible by psychiatric progress that promised to return the mental patient to social conformity (Barham, 1997: 12).

### Policy Initiatives

Deinstitutionalisation, as part of health care policy has come to mean cyclical re-institutionalisation in what is known as 'the revolving door of mental health care.' Shorter hospital stays to stabilise psychotic symptoms before release into a network of community-based centres until the onset of more severe symptoms reconfigures deinstitutionalisation as chronic reinstitutionalisation. In this way deinstitutionalisation is implicated in the conceptualisation of the chronicity of schizophrenia itself (Estroff, 1993).

Traditional, formal psychiatry relied on institutionalisation to effect proper treatment. Changes in treatment since about 1955 have allowed schizophrenics to live within the general population:

The mentally ill are no longer a distinct and separately administered population: they are absorbed into the ranks of a homeless, or temporarily and precariously housed, indigent urban population (Knowles cited in Macdonald, 1997: 12).

However, the closing of the asylums has not meant the complete absence of institutions, but instead shorter hospital stays of a cyclical nature for the mentally ill (Macdonald, 1998; Bachrach, 1994; Lamb, 1988 & 1993). For many, the revolving door of institutionalisation and deinstitutionalisation has created points of repeated rupture. Institutionalisation, originally intended as curative became a custodial tool of the welfare state (Barham, 1984: 23). Deinstitutionalisation became the death knell of institutions as either places for convalescence or custody, signalling the decline of the welfare state's instrumentality and the rise of "stop gap" treatment centres.

Psychiatry uses diagnostic categories to mobilise power. "to judge individual competence, to name with diagnostic labels and to 'manage' with a pharmacological armoury" (Knowles, 1996: 57). Psychiatrists themselves are however largely absent as immediate or front-line caregivers.

Traditionally, the administration of mental distress – the diagnosis accuracy, and the treatment effectiveness – was done at the expense of the users' perspectives: formal psychiatric knowledge does not necessarily entertain the lived experience of patients.

The re-alignment of mental health services has meant that most psychiatric patients are now managed by drugs via a general practitioner and few see a psychiatrist on a regular basis (Macdonald, 1997: 30).

In addition, the post-war era had seen tremendous expenditures on health care and specifically in Canada, the development of a social-welfare net that included universal health care. Direct costs in terms of health care is just one among many factored into considerations about the delivery of services for schizophrenics.

Schizophrenia is the number one mental illness in Canada expected to afflict approximately 270 000 Canadians in their lifetimes (BCSSb: Doubt, 1996: x). Costs associated with lost productivity and family financial burdens are estimated at \$6-billion (Clarke Institute, 1998). Accounting for 3.6 million hospital days (1989-90) or 30.2% of all hospital stays for mental disorders (Health Canada, 1993), estimated costs run upwards of four billion dollars yearly: \$2.3-billion in direct health-care cost; \$2-billion in welfare, family benefits and community services (Gadd, 1997).

Hospital expansion has come to mean the increased institutionalisation of professions and health care workers while at the same time the release of inmates. As one social worker informant observed, "they released the schizophrenics but not the professionals." Although schizophrenics are increasingly found in drop-in centres, missions and on the streets, the professionals, particularly psychiatrists have remained cloistered in their institutions.

Deinstitutionalisation as a movement shifting long-term psychiatric care away from formal, usually state run institutions, to community based organisations and programmes is

a general trend in most Western countries and in accordance with the policy suggestions of the World Health Organisation. Understood as an effort to improve services and treatments for the mentally ill, deinstitutionalisation is also in line with most governments' budget cutbacks and zero-deficit targets since it implies the closing of these state funded institutions. In Quebec, where mental health problems are the second most common reason for hospitalisation and have the highest rate of public expenditure relative to any other health problem, deinstitutionalisation is meted out in policies aimed at more than halving average hospital stays (from 33 days to 16) and closing half of all psychiatric beds (from a high of 6000) by the year 2002<sup>5</sup>.

In Canada, jurisdiction over health is a fragmented field shared by provincial and federal departments. Nationally, there is neither a health insurance programme nor federal mental health centres. National standards are set through Health Canada and a fraction of provincial health budgets do come from the federal government, which by controlling this funding has a voice in provincial health-care policy. It was however a series of federal initiatives that began the movement to community based care. In 1954 Health and Welfare Canada recommended the integration of provincial mental hospitals into general hospitals and the development of community-based services (Goodwin, 1997: 14). This was followed in 1964 by a recommendation of the Royal Commission on Health Services that all patients in provincial psychiatric hospitals be moved to general hospitals (Wasylenki *et al.*, 1994: 21).

Where policy met practice was the shifting of non-acute care patients to general hospitals. Provincial psychiatric hospital beds are maintained for the acute care of otherwise difficult to manage patients. What constitutes a difficult to manage patient is however also

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<sup>5</sup> In the current state of "health-care crisis," these figures are under review and already the government has decided that contrary to preliminary report suggestions, hospital stays should be reduced to 20 days by the year 2002, not the 15 originally suggested (Derfel, 1999: A6).

partly defined by the success of drug regimes aimed at the manageability of the patient and not necessarily their illness.

By the 1970's, the expense of maintaining two hospital systems lead to a more concerted effort to close provincial asylum beds while establishing community programmes.

Although we are still caught up in the process of shifting responsibilities, our current situation finds us with three areas of service: the community-based centres, the psychiatric wards of general hospitals, and the provincial asylums. More important though are the wider and more profound gaps between them. While both hospital systems remain staffed by professionals with a high percentage of doctors, community-based centres are often the major access points to service but are usually staffed by volunteers and social workers. This scenario may be the overriding reason why although over 90% of Montreal's schizophrenic population live outside hospitals, most provinces<sup>9</sup> spend only 10-20% of their health care budgets on community services (Goodwin, 1997: 102).

Although institutions are emptying, community-based alternatives are being created at a rate unable to meet the new demands. Even the most ardent supporter of community-based mental health programmes is still forced to acknowledge that it is easier for patients to use better-funded hospital-based programmes, particularly localised ones of centralised authority. In addition, homelessness as "a symbol of the deinstitutionalisation process that failed" (Dear and Wolch, 1987: 195) has increased among the mentally ill. Wasylenki states that 20-30% of homeless people suffers from mental illness (Wasylenki *et al.*, 1994: 22). Interviewed workers said that anywhere from 40% to 75% of their users exhibited various degrees of mental illness. As homelessness indicates, deinstitutionalisation is not in itself a process of social reintegration. Concerning the real cost of deinstitutionalisation,

John Martin wrote the following:

To say that deinstitutionalisation increases community integration is a myth. It is a basic characteristic of those who suffer from severe psychiatric illness to shun society. They are not likely to become integrated into the

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<sup>9</sup> Saskatchewan spends approximately 50%.

community at large. On their own, they will isolate themselves in their apartments, or they will huddle in small groups of equally psychiatric patients in donut shops. The severely ill need the protective and sheltered artificial community that can be created in a hospital environment. They will be worse off living independently in the community (Martin, 1998).

Interviewed workers expressed concern about the consequences of a system so driven to deinstitutionalise. Many had stories of people, who clearly still needed institutional care, literally being released into a cab and showing up at a drop-in centre's door. Martin does indicate the deinstitutionalisation is not universally good and alone cannot achieve reintegration of the mentally ill. Deinstitutionalisation is a public health-care policy shift not necessarily converging with the needs of the patient and his illness.

In Quebec, deinstitutionalisation has been part of provincial health care policy since the 1962 Bédard Report which "advocated deinstitutionalisation, community psychiatry, the definition of catchment areas, multidisciplinary teams, a better psychiatric educational system, and an increase in the number of psychiatrists" (Mercier and White, 1994: 42).

Community care in Quebec has evolved from a situation in which religious communities owned and ran French services while English services relied on community associations and philanthropy, to the present one administered largely by the system of CLSC's<sup>7</sup>, community service centres. Quebec is the only province with a social services network system, serving to integrate and often co-ordinate hospital care, rehabilitation, convalescent centres and social services agencies. Co-ordinated by the provincial Ministry of Health and Social Services, CLSC's are autonomous units and are mandated by law (Mercier and White, 1994: 41).

### **The Virage**

Diane Gauthier who is in charge of mental health for the Montreal Regional Health Board states:

We can say there has been a clear improvement in mental-health services over the past ten years. If we look at the Montreal region, there were a lot of people who were hospitalized. We have improved the quality of service and

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<sup>7</sup> Centres Locaux pour les Services Communautaires

reduced the length of hospital stays (in Derfel. 1996b: A6).

Advances in medicines and budget cutbacks are contributing factors to deinstitutionalisation that is itself one of the successes that Gauthier touts. At the same time media reports such as the one about a schizophrenic who pushed a woman before an oncoming train in the Toronto subway elicit a strong reaction from a public that fears the potential disasters of deinstitutionalisation, yet supports the budget cutbacks driving it. Implicitly a plethora of social problems (e.g. unemployment, homelessness, substance abuse) are linked with that of mental illness.

As I write this thesis, Quebec is in the middle of a health care crisis. Hospital emergency rooms are operating beyond their capacities and the government has announced a plan to inject twenty million dollars into health care. Although I think that generally most Canadians believe that there has been a decline in the quality and availability of health care services due to budgetary cutbacks, this crisis as the government would have us believe is some sort of growing pain from the "*virage ambulatoire*" or the movement away from institutionally delivered extended health care.

In an effort to cut \$190 million from its annual expenditures, the Montreal-Centre Regional Board has embraced the ambulatory shift as, "the shift to quality ambulatory-care services by providing alternatives to hospitalization or by speeding the person's return to his accustomed surroundings following hospitalization or surgery..." (gov.qc (a), 1999).

Although this shift may be motivated by cutbacks and directed at health care in general, it needs to be noted again that the results and inevitable effects of this turn even as the government intends them, is the result of a shift in public policy: one ostensibly meant to keep pace with medical advances but neither necessarily driven by, nor a result of them.

As this reorganisation plan effects mental health, the governments web page states:

The number of clients with intellectual impairments living in the community instead of institutions is growing. The Regional Board supports this trend and is working to develop more alternatives to hospitalisation and to round out the regional range of services now provided. Although the Montréal-Centre region adopted a regional mental-health services organisation plan, the organisation of services has remained practically the same as it was five



years ago: all services outside the hospital are underdeveloped. Achieving a new balance in this sector therefore requires a real continuum of services by emphasizing the development of alternatives to hospitalization and by completing the regional range of services through reallocation (*ibid.*).

According to this document, \$23 million will be spent on improving health services. Particularly interesting is the note that in 90% of the cases, mentally ill patients in more than 200 acute care hospital beds who exceed a stay of 120 days could be returned to "their home environment" if "community-based services" were available. The document also recognises that psychiatric care hospitals have a limited ability to vary treatment lengths and intensity because their role is primarily one of hospitalisation and outpatient clinics. This means that new ways of delivering short term psychiatric services need to be developed.

By "community-based services," the board appears to be relying on geographically informed definitions of community such as those of the CLSCs' catchment areas. Community-based services serve members of a community living in a specific geography. One mission I visited had seen an increase of mentally ill users from between ten to twenty percent, to fifty percent. The fact that being returned to a "home environment" may ultimately lead to homelessness and ineligibility for community membership is not figured into such policy.

An "interactive network" of psychiatric hospitals, acute-care hospitals, CLSCs, intermediate resources and community organisations is intended to provide continuous, long-term support to socially reintegrate people with mental health problems. To this end the Regional Board also adopted seven measures regarding mental-health services:

- Socially reintegrate patients residing at Louis-H. Lafontaine hospital, providing appropriate services;
- Maintain 1,124 psychiatric acute-care beds for adults: 672 for general services and 452 for specialised and ultraspecialised services;
- Develop a greater range of psychiatric hospital services;
- Increase community-based mental-health services;
- Develop mental health services for specific clientele: the homeless, people with mental-health problems who commit offences and the autistic;
- Set up an interactive mental-health services network;
- Adjust budget cuts to psychiatric hospitals (*ibid.*).

Often during the research, workers spoke of noticing an increase of young people using community services and the declining wealth of Montreal. In addition, some workers spoke of Montreal as a unique city for attracting those who need access to such services because as a city it offers more resources than the regions. Montreal is also thought to be the first choice among francophones<sup>3</sup> who unlike anglophones feel ill at ease shifting between large urban English-speaking centres throughout the country. At some juncture, statistics and fiscal restraints by way of the policies they have informed, intersect or collide with the functioning of these policies. Health care policies established how ambulatory care is to be delivered. However, under our system of universal health care, policies aimed at the delivery of service involve creating narrow access points ("first-line care") to these services. These policies also allocate resources to professionals to meet the exigencies of their profession as well as the mandate of the policy. Who delivers the care, to what extent and for how long are just some of the questions hidden in the "how" it is delivered. When one social worker informant commented that the schizophrenics, but not the professionals (psychiatrists) left the institutions, she suggested that psychiatric care is increasingly under the purview of non-psychiatrists.

The ambulatory shift has been more than a change in the delivery of services. It is predicated on an underlying assumption that not only are there different ways of delivering services, but different people (providers) to do so. This forces a whole new network on the system, a new set of roles and relationships for users and providers alike and a new set of assumptions and expectations.

The ability of psychiatry to diagnose and label also comes bundled with the power to institutionalise and deinstitutionalise and hence makes psychiatry answerable to fiscal

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<sup>3</sup> According to the Regional Board, 70% of all immigrants to Quebec settled in the Board's jurisdiction. The "ethnolinguistic" breakdown of the population is 56% with French as their mother tongue and 20% with English as their mother tongue. Of the remainder, approximately 21% spoke English or French as a non-native language, leaving 3% of the population who could communicate in neither language (gov.qc (e.f), 1999).

restraints and subject to the pursuits of public policy. Schizophrenia is the most costly disease in terms of direct spending associated with hospitalisation and indirect costs associated with lost productivity. Schizophrenia occurs at the age when investments in individuals in terms of education and training are expected to pay off in the form of employment opportunities and the raising of a family (Health Canada 1991). Although there have often been severe hospital budget cutbacks and a dramatic shift to voluntary community organisations, there have been huge increases in the training and hiring of professional health care workers such as psychiatrists, psychologists and social workers particularly. In the United States, from 1976 to 1984, staffs with professional degrees have increased 100% (from 100,886 to 202,474) while those workers with less than a B.A. have declined 21% (from 140,379 to 110,769) on average at mental health organisations (Witkin *et al* cited in Estroff, 1993: 269). Referring to Mechanic and Aiken, Estroff concludes that two-thirds of many states' mental health expenditures are on inpatient care while three-fourths of those using public services do so through community organisations (Estroff, 1993: 269). Since the Bédard report of 1962 the number of psychiatrists has jumped five-fold (Mercier and White, 1994: 42).

The reduction of available hospital beds and shorter stays in them is a result of health care policy shifts, *la virage ambulatoire*. Budget cutbacks have resulted in closed hospital beds while advances in biomedicine and pharmacology allow us to invest in the belief that those beds were empty anyway. Such policy shifts are not directly concerned with the health of the patients but rather that of the economy.

The creation of the clinical schizophrenic and the treatment made available to him/her is the development of a specific history. The "schizophrenic at liberty" (Burton *et al.*, 1974: 5) is the product of our current mental health management system geared towards the treatment of schizophrenics. Public policy, professional demands and shifts to community-based centres to provide services are the current forces guiding this system. This system is itself something of a disputed tool and is a collage of different histories.

Some of the intersecting vectors of these histories are: the confinement imprisonment of the mentally ill: the rise of reason and rationality especially in opposition to madness: the emergence of the clinical setting and the body as a source of both disease and knowledge: the emergence of a profession that was able to endow itself with the ability to fix diagnostic labels: how beliefs in cure and treatment have all been altered by technological advances and reconceptualisations of cure, convalescence and welfare: and the drive by policy initiatives largely to meet fiscal restraints.

## Chapter 4 - Schizophrenia as Disease

This chapter focuses on the criteria for a diagnosis, the attachment of the label "schizophrenic." This diagnosis is an important transition in the lives of schizophrenics who will have to cope with a chronic disease that may overwhelm their lives. Barham suggests that unlike with other curable diseases, when one asks what the patient was before, during and after the illness, one discovers that for the schizophrenic, there is no after (Barham, 1997: 88). Diagnosis then does not mark a watershed separating periods of wellness from illness. Diagnosis is an explanation for a particular way of being. How this way of being is clinically assessed and distinguished from other ways of being is the focus of this chapter.

Psychiatry understands schizophrenia as a biological disease. David Morris states that "contemporary medical textbooks define *disease* as an objectively verified disorder of bodily functions or systems, characterised by a recognisable cause and by an identifiable group of signs and symptoms" (Morris, 1998: 37).

The *Diagnostic and Statistical Manual of Mental Disorders*<sup>9</sup> (VI) includes schizophrenia with other psychotic disorders which is to say that psychosis is a defining feature of schizophrenia (DSM VI, 1994: 273). Other psychotic disorders include, "Delusional" and "Substance-Induced Psychotic" disorders. In contrast, "Cognitive" and "Mood" disorders do not have psychotic symptoms as defining features.

As with most of the informants, when a schizophrenic says, "I hear voices," he or she is expressing one of the most common psychoses and a symptom which medication is geared to suppress. The successful suppression of symptoms and lack of a psychotic state does not however mean that the person is no longer schizophrenic until such time establishes the unlikelihood of psychotic relapse. The fact that the DSM establishes

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<sup>9</sup> The DSM for short.

psychosis as essential to a diagnosis of schizophrenia yet acknowledges periods of non-psychosis as part of schizophrenia is fundamental to the creation of a chronic schizophrenic in whom the disease's continuity is maintained through periods of illness, recovery and wellness.

The inadequacies of the term "schizophrenia" were apparent almost immediately after the term was coined by Eugene Bleuer in 1908 to "refer to a break with reality caused by disorganisation of the various functions of the mind, so that thought and feelings no longer worked together normally" (Carlson, 1994). Literally schizophrenia means, "split mind" and is commonly confused with a split personality. In addition, popular understandings of the disease are corrupted through the media as in news reports of violent schizophrenics and movies such as "One Flew Over the Cuckoo Nest."

It is unclear whether schizophrenia is one disorder or several with different causes. Few generalisations hold true for all people diagnosed with the disease. Schizophrenia is thought to be a biological disorder of the brain, with strong inherited factors although the degree to which genetics may predispose someone to schizophrenia is unknown. However, the majority of work on schizophrenia appears to be moving increasingly towards identifying the gene responsible. (Psychiatric texts on schizophrenia often reference texts with titles such as, "Mapping Genes for Psychiatric Disorders", "Genetic Approaches to Mental Disorders", "Localization of a Susceptibility Locus for Schizophrenia on Chromosome 5", etc.). In addition, psychiatric research on schizophrenics frequently involves measurements that are straight out of eugenics theory with the measuring of head circumference, body weight, body length, and shoulder circumference. Such research dominates much of the psychiatric discourse at the expense of alternative work not the least of which is environmental factors.

Diagnosis of schizophrenia relies not on biological assessments but rather on observation of a variety of symptoms with reference to the diagnostic criteria established by

the DSM. The expression of these symptoms varies greatly from one individual to another and no one symptom is common to all people.

Schizophrenia is manifest in various behaviours that in turn are seen as symptoms of the disease. Symptoms are generally organised by the DSM into two categories. Positive symptoms are those excess behaviours which the schizophrenic exhibits. Generally they are internal thought processes and can be masked or hidden from others. They include hallucinations and delusions. Negative symptoms are those behaviours that the schizophrenic appears to be lacking and behaviours that have social significance such as withdrawal. These include alogia, affective blunting or flattening, anhedonia and attentional impairment which are defined later.

The following text is taken directly from the DSM (IV) and is meant to briefly summarise how a diagnosis of schizophrenia ought to be approached (DSM IV, 1994: 285-286)

#### Diagnostic criteria for Schizophrenia

1. *Characteristic symptoms*<sup>10</sup>: Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):
  - I. delusions
  - II. hallucinations
  - III. disorganized speech (e.g., frequent derailment or incoherence)
  - IV. grossly disorganized or catatonic behavior
  - V. negative symptoms, i.e., affective flattening, alogia, or avolition
2. *Social/Occupational dysfunction*: For a significant portion of time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relationships, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
3. *Duration*: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1-month of symptoms (or less if successfully treated) that meet Criteria A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criteria A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
4. *Schizoaffective and Mood Disorder exclusion*: Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently

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<sup>10</sup> Actual definitions for these symptoms are provided following this section from the DSM.

with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

5. *Substance/general medical exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
6. *Relationship to a Pervasive Development Disorder:* If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Some psychiatrists argue that many symptoms within these two categories can actually be used to create a third category. Although the DSM maintains only two categories, for my purposes, I have adopted the use of three categories as presented by Young and McGorry. Disorganisation is this third group of symptoms. Disorganisation disrupts thinking, speech, behaviour and affect. The following definitions are compiled from Andreasen (Andreasen, 1984 & 1990):

### Positive Symptoms

Hallucinations are sensory experiences that do not correspond to reality and may be auditory, visual, olfactory or tactile in nature.

Delusions are false beliefs that cannot be explained on the basis of the subject's cultural background. The most common delusions include: thought withdrawal where the subject feels that thoughts are being pulled out of his mind; thought insertion where the subject feels that thoughts are being inserted into his mind; thought broadcasting where the subject believes that others can hear his thoughts because they are being broadcast; persecutory beliefs where the subject believes he is being persecuted or conspired against; grandiose beliefs that he has special powers or abilities. Other delusions may be: religious in nature: a belief that his body is abnormal or diseased (somatic); overemphasis on significant comments, remarks or statements which the subject feels refer to him; delusions that his feelings and/or actions are being controlled by others; delusions that others can read his mind; delusions of guilt stemming from the belief that he has committed an unforgivable crime or sin.



## **Negative Symptoms**

Alogia is a poverty of speech or content such that there is either a reduced amount of speech or a normal amount of speech but with a reduced number of ideas.

Affective blunting and flattening are terms used to indicate an inability to express emotion fluidly and richly.

Avolition is a lack of motivation to initiate and carry through behaviour.

Anhedonism is the loss of capacity to experience pleasure or enjoyment.

Attentional Impairment is an inability to focus attention.

## **Disorganised Symptoms**

Derailment is when ideas switch to an obliquely related or totally unrelated idea: they are unclear or confusing connections between sentences and clauses.

Tangentiality refers to replies to questions and not to transitions in spontaneous speech. Specifically it implies replying in a distant or unrelated way to a question.

Incoherence refers to when words and phrases are joined together incoherently within a sentence or clause.

Circumstantiality is different from derailment in that the speaker eventually reaches the point. Indirect speech and excessive use of detail mark circumstantiality.

Pressure of speech means speaker speaks rapidly and is difficult to interrupt.

Distractible speech is when the speaker is easily distracted by nearby stimuli and stops speaking in the middle of a sentence or idea and changes the subject to respond to the distraction.

Clanging means that speech is difficult to understand. Redundant words are used and sounds rather than meaning govern word choice.

Illogicality refers to a pattern of speech in which conclusions are reached which do not follow logically.

Disorganised Behaviour is behaviour seen to be unusual or bizarre and is most readily witnessed in clothing and appearance as well as social and sexual behaviours.

Incongruous or Inappropriate Affect refers to the display of emotion considered inappropriate for the situation.

Negative symptoms occur earlier on in the illness than the positive symptoms. Their assessment however can only take place when the person is brought before a psychiatrist.

Negative symptoms are difficult to assess for a variety of reasons.

Although quite ubiquitous in Schizophrenia, negative symptoms are difficult to evaluate because they occur on a continuum with normality, are non-specific, and may be due to a variety of other factors (e.g., as a consequence of positive symptoms, medication side effects, a Mood Disorder, environmental understimulation, or demoralization) (DSM 1994: 277).

Excitement, grandiosity, suspiciousness and hostility may be excused by family members as part of a good or bad day. Delusions and hallucinations are often associated with drug use rather than a schizophrenic diagnosis and intervention on the part of families may therefore be misguided, usually ending in failure and the ejection of the person from the household. Hostile actions involving police intervention may take several arrests, fines, jail time and releases before a diagnosis is given (Clausen, 1956: 13-18). Since all these symptoms are of the later occurring positive symptoms, intervention rarely happens at the early phases of schizophrenia. It may also seem that the symptoms taken to indicate schizophrenia can only be subjectively assessed, and even then with great difficulty since many of the symptoms may only seem bizarre in term of excess. In other words, many of the symptoms seem to be part of a range of behaviours that in themselves are not irregular but may be interpreted as irregular if extreme or overwhelming.

Pharmaceutical research holds several theories such as over activity of dopamine receptors in the brain, elevated levels of serotonin and enlarged lateral ventricles as causes of schizophrenia. Although the complexity and mystery of the brain prevent a full understanding of the implications of these discoveries, they are important for several reasons. Firstly, the effectiveness of antischizophrenic drugs is one reason to argue for schizophrenia as an illness since the drugs are mainly effective only on schizophrenics and not necessarily on non-schizophrenic patients who nonetheless exhibit schizophrenic

symptoms. Secondly, the affects of "recreational drugs" such as LSD and cocaine in simulating some schizophrenic behaviour are known. It follows then that medication which works in the opposite fashion of these drugs, such as ones which reduce dopamine activity, would be effective in treating schizophrenic symptoms. However, returning to the list above, those "simulated schizophrenic symptoms" are classified as positive. Treatments for negative symptoms are more precarious and rely on medications that are not used solely on schizophrenics but rather on a range of people with mental illnesses. Thirdly, motor dysfunction resembling those associated with Parkinson's disease is a common side effect of antischizophrenic drugs. This in itself is of major importance since the development of new drugs is facilitated by making drugs whose molecular structure resembles that of known antischizophrenic drugs. When testing new drugs on lab animals, those that produce motor disturbances are investigated further, making motor disturbance and treatment for schizophrenia inextricable. At the same time, this fosters a need for more drugs to deal with such side effects (Carlson, 1981: 670-676). Drug treatments treat symptoms of schizophrenia while others treat side effects. Suppressing delusions is not a treatment aimed at curing the disease that causes the delusions. Anti-psychotic drugs are nonetheless considered one of the most important medical advances of this century and form the backbone of treatment for schizophrenics. Finally, although absolute biological causes of schizophrenia may be elusive, they make for the defining of a disease. Schizophrenia by most accounts is a biological brain disorder.

One informant, Laurent, throughout his interviews referred to himself as "*psychiatrically ill*" and once as being "mentally handicapped." His story also included many references to drug treatments and his personal medical regime. Psychiatry and mental illness were closely associated with drug treatments. In fact, the authority to prescribe drugs is one feature of psychiatry that distinguishes it from other closely related caregiver professions such as psychology and social work. For Laurent as with other informants, having a psychiatrist who prescribed drugs was already part of the proof of schizophrenia.

In this way, schizophrenia is as much a disease as it is a relationship with a particular type of professional.

Although little is known about the causes of schizophrenia or its impact on the brain, schizophrenia is thought to be a biological brain disorder which manifests itself in a variety of behaviours. These behaviours are used by psychiatrists relying on a set of diagnostic criteria to assess and diagnose schizophrenia and to treat psychosis. The diagnosis of schizophrenia occurs after the onset of symptoms, making that diagnosis part of a journey into madness and linking it to a particular relationship with professionals.

## **Chapter 5 - Schizophrenia As Illness**

This chapter explores what it could be to be schizophrenic, that is, what schizophrenia is as a subjectively experienced illness rather than as what the clinical disease may be manifest. Whereas the previous chapter explained the psychiatry behind the diagnosis, this chapter looks at the psychology of the illness. An idea of what schizophrenia could be as a psychopathology of common sense and where it could be located in our epistemology is also offered in this chapter. As part of the alternative to the list of symptoms from the DSM, presented here is a projected course of schizophrenia and an architecture for the schizophrenic lifestyle.

The criteria of the DSM allow psychiatrists to verify the presence of the disease of schizophrenia by objectively observing the presence of a group of symptoms. Even if the intersubjectivity between patient and doctor is denied, the experience of schizophrenia itself is the subjective experience of what the DSM lists as symptoms. These symptoms are understood by others (such as the schizophrenic and those around him/her) as behaviours. Schizophrenia as an objectively verifiable disorder seems to leave little room for the pre-diagnosed schizophrenic's subjectivity in the analysis and assessment of the disease. This is part of the exigencies of psychiatry and its pursuit of objectivity. But what, if any, alternatives are there for diagnosing schizophrenia and subsequently the experience of it? Reconceptualising schizophrenia as a psychopathology of 'common sense' presents not only an alternative for understanding but so far as it may require a different profession to assess the "illness," it also suggests a different way of diagnosing.

### **The Psychopathology of Common Sense**

There are variations between understandings of schizophrenia throughout the world, most noticeably between American and European psychiatrists. These differences are slight (van den Bosch, 1995) and in any case, this paper is more concerned with what happens after a diagnosis and how the stigma insinuates itself in repercussions. What is interesting

is that schizophrenia should fall so utterly under the purview of psychiatry and not (for example) within the epistemology of psychology.

I miss the natural way of taking things for granted (...) One's manners, humanity, sociability, these are all rules of the game which one should follow: for me they were not clear (...) I don't know how to tell (...) It's not knowing (...) After all, every child knows that! It goes with you naturally, doesn't it? (in van den Bosch, 1998).

For van den Bosch, a psychopathology of common sense provides a segue into a different exploration of what schizophrenia could be. The preceding quote is an example of this psychopathology of common sense, which van den Bosch elaborates in the following way:

The disorder affects the pragmatic use of things. Common knowledge has no precise meaning and judgement of social and emotional situations is impaired. As a result, basic communicative skills like social intuition, appreciation of humour, naturalness and automaticity in social interactions are lacking.

Although this may again seem like a blanket observation glossing over individual manifestations and cyclical phases, van den Bosch offers a shift away from cognitive task functioning to the subjectivity of the schizophrenic.

The German concept of 'basic schizophrenic symptoms' encompasses elements of the subjectively experienced lack of spontaneity and automaticity, as well as primary cognitive disorders.

Van den Bosch appeals for a neuropsychological approach to schizophrenia.

Researchers usually describe the basic neuro-integrative deficit in terms of laboratory findings on the cognitive tasks, but it is also a subjective experience. The subjective domain has been neglected in the cognitive tradition, but it is time for a revival. We need an analysis of the experience of the schizophrenic patient to provide refinements that are not available in the traditional diagnostic approaches. After all neuro-psychology has profited from the detailed ideographic analysis of subjective experience and there are good reasons for considering schizophrenia a complex neuropsychological disorder.

Practically it needs to be asked how easy it is to move from psychiatric disorder to neuropsychological disorder. Schizophrenia seems to be a sort of 'illness foundation' in which psychiatry is rooted. Treatment relies on prescription drugs and the power to prescribe is bestowed on psychiatrists. Deinstitutionalisation has brought schizophrenics

closer to social workers, psychologists and other professionals mapping out schizophrenia as a disputed epistemological territory. Added to this is the shift in psychiatry to hermeneutics. Nonetheless, the DSM as the only authoritative guide to diagnosing mental disorders implies that psychiatry is its own complete paradigm without alternative models and it is therefore hard to imagine schizophrenia coming under the purview of another profession. Thomas Szasz, throughout various writings, suggests that psychiatry as a complete paradigm is more likely to undergo refinements and offer exemptions rather than to be blindsided by an epistemological shift. Each of the *Diagnostic and Statistic Manuals* can in fact be viewed as a refinement.

### **Disease versus Illness**

Morris contrasts the medical definition of *disease*, given earlier (p.42), with that of *illness*. Illness he defines as indicating, "the patient's subjective experience, which may or may not indicate the presence of disease" (Morris, 1998: 37). Both definitions are from a biomedical epistemology and serve here to underscore once again the different vectors of power and control of the psychiatrists and schizophrenics. While the doctors manage a disease, the schizophrenics experience their illness.

Schizophrenia is both a modernist and postmodernist project. The very diagnostic tools deployed in naming schizophrenia are the culmination of the rationalisation of psychiatry (Burton *et al.*, 1974). The "technocracy in command of the mental health establishment" (Kovel, 1987: 334) created the modernist clinical setting. Within this setting both the disregarded intersubjectivity between patients and clinicians, and the quantifying of reason, allowed for the measurement of madness. Western definitions of a successful self involve "psychic unity, autonomy, self-containment, full possession of thought, and willed, rational, purposeful action" (Barrett cited in Barham, 1992: 89-90). Investment in western notions of a unitary, individualist, permanent and authentic self (Geertz, 1984; Taylor, 1989, 1991) shed of spirituality denies any legitimacy to the experience of psychosis. This modern self, abandoned of the possibility of psychosis

leaves that experience to an 'other' self and makes that other self vulnerable to the diagnosis of clinical illness. Or, more to the point, the rational self makes clinical illness the only available explanation of psychosis as it stands in conflict with rationality and psychic unity. This understanding of a normal, rational individual is the benchmark for an assessment of illness which in many ways is a deviation of this individual. This prototype of normality underlies the supposedly atheoretical classificatory systems of American psychiatry (Lovell, 1997: 356). When the modern, rational self left room for the experience of psychosis he laid claims on the ability to understand and treat that psychosis for himself by way of the rational, medical model and ultimately denied the subjectivity of persons experiencing schizophrenia.

Meanwhile, the schizophrenic lifestyle is itself a post-modern metaphor. Schizophrenia as a mental illness entails both the disordering of psychological processes and the deviation of behaviour from the norms of society (Clausen, 1956: 13). Although psychiatrically, deviations from these norms may be symptomatic of a mental illness, it is in conflict with these norms that schizophrenics are most likely to experience themselves as schizophrenic (different). Recognising that there is more to the experience of illness than the medical model can explain is the beginning of the post-modern experience of illness (Arthur Frank cited in Morris, 1998: 24). Brain dysfunction, delusions and fragmented thinking are escapes from rationality and can be reconfigured as the unfettered experience of the post-modern individual (Lovell, 1997: 355). The post-modern self is reflected – or anticipated – in the multi-referent collage of fragmented delusions of the schizophrenic.

Schizophrenia, as a psychiatric disease and an experience of illness, allows for the exploration of the tensions between modernity and post-modernity: the modernist practices of traditional psychiatry and the post-modern experience of schizophrenia.

The development and widespread use of anti-schizophrenic drugs in the 1950s has meant the general deinstitutionalising of schizophrenics, fundamentally altering the way schizophrenics live and are administered to by their care givers (Bachrach, 1994; Talbott,



1994). This alteration has in turn loosened the reigns of psychiatry, leaving psychiatrists primarily responsible for diagnosis while community organisations and family are left with the exigencies of caring for the mentally ill (Knowles, 1997b).

The emergence of patients' rights groups in the 1980s has also provided a powerful voice for the patients themselves by attempting to question the authority of diagnosis as well as the effectiveness of care while challenging the stigmatisation that goes along with any diagnosis of mental illness.

Schizophrenia as a diagnosis is expressive of identity and knowledge. Psychiatry is its mechanism of construction and reproduction making itself indispensable to the illness and overriding individual differences and similarities by favouring generalisations of organic pathology. Schizophrenia then, functions as a category: but what essentially does this category mean? How does it function daily in the lives of those who work and live within its constraints? What performances does it require and what relationships does it create (Sedgwick, 1990: 27)? Diagnostic categories are power vectors used to judge and manage (Knowles 1997b); in the case of schizophrenia the power resides largely with psychiatrists but like all powers that be, they also face points of resistance. Questions then arise such as: 'In what form is this resistance established?' 'By whom and on whose behalf?'

Increasingly a loose network of services is being asked to provide for "schizophrenics at large" creating non-psychiatric "experts" from the social worker to the shower attendant. In an era where psychiatry itself is being questioned, schizophrenia is evolving beyond merely a diagnosis and is now a highly contentious marker whose meaning is increasingly nebulous and constantly negotiated. Assertions of self, identity secrecy and disclosure on the part of the patient, professional exigencies, scientism and limited resources on the part of a variety of professions are all either agitated by marginality, societal fears for safety, police and legal interventions (Boyle, 1990; Clausen, 1956), and a pharmaceutical

drug culture, or mitigated by mutual understanding, better treatments, social integration as well as improved and accessible services.

One social worker at a drop-in commented that all the mentally ill users there had been in jail.

I can't hardly think of one person over at the centre that is mentally ill and that has not been in jail at least one time at the very least.

By linking schizophrenia with criminality Beth indicates how some factors such as legal intervention, and failed social integration establish the inevitability of jail time for the mentally ill. The folding in of criminality into the sickness role provides one example of how a diagnosis, with close associations to an inevitability, charts a sort of life course. This course is most likely mapped out with a series of inevitabilities of which homelessness, estrangement and unemployment are but a few. When one informant alternatively stated that she was "crazy" and "well" she was struggling to explain both how schizophrenia persisted in times of non-psychosis and the permanent alteration of her life after diagnosis. That permanent alteration is the inescapability of a sick role. It is this sick role and the fusion of self with disease that can only become the subjective experience of illness. Diagnosis is the exposure of subjective feelings and thoughts (which since they are one's own and the only ones one may experience, seem normal) to the medical gaze and in many ways is the erosion of what separates secrecy from disclosure. Full disclosure in turn is part of what expectations are based on and in the case of a schizophrenic diagnosis, one part of what will be presented here as five-phase course.

This five phase course pulls together what the psychiatrist knows about the schizophrenic (a diagnosis), what they may suspect (causes and onset) and what they may expect (recovery, stability and relapse). Not only does this expand schizophrenia beyond the psychotic symptoms, but it can leave a lingering sense of disease/illness even when the schizophrenic is asymptomatic. It is also a means whereby unemployment, homelessness, depression and other problems can be anticipated in various phases regardless of their relevance to schizophrenia or particular schizophrenics. In this way, the life of a

schizophrenic, as a subjective experience, is also inevitably the experience of disease and illness.

If symptoms represent schizophrenia as a mosaic of illnesses, then the course of schizophrenia presents a trajectory leading up to, including and following through the symptoms. Breaking the course of schizophrenia into phases that include what happened before diagnosis and is likely to happen after, this course is both a projection and a backward glance. Although statistically approximately 5% to 15% of schizophrenics *fully* recover (have no residual symptoms), the vast majority will struggle with schizophrenia for the duration of their lives. For this majority then, not only are there expectations concerning the effect of schizophrenia on the rest of their lives, a forward projection, but theories abound about the causes and predispositions to schizophrenia in the individual as well as the trigger of the first psychotic episode.

### Phases of Schizophrenia

This section introduces the five phases of schizophrenia. Because they are states of being and include periods before and after the onset of florid symptoms, they speak more to the psychology of the schizophrenic than the psychiatric symptoms of the disease.

The premorbid phase begins before the first signs of an illness and is closely related to the source of the illness. Although it is unclear what causes schizophrenia, in keeping with medical and biological models, the premorbid phase suggests that prenatal or early postnatal brain development may be the source of the illness (Weinberger, 1995).

The prodromal phase is the interval between unusual behaviour and the onset of psychotic symptoms. The prodromal phase is subject to intense clinical research because studies suggest that early intervention and treatment during prodromes, greatly increases the opportunity to alter or mitigate the course of schizophrenia. However, this phase also usually coincides with adolescence making detection of unusual behaviour difficult to assess, as they may be confused for "growing pains." The following is a list of prodromal features in descending order of frequency (Yung and McGorry, 1996).

- Reduced concentration
- Shortened attention
- Reduced drive and motivation
- Depressed mood
- Sleep disturbance
- Anxiety
- Social withdrawal
- Suspiciousness
- Deterioration in role functioning
- Irritability

The psychotic phase is the manifestation of active illness, characterised by the symptoms described as, "positive," "negative," and "disorganised." It is this phase for which neuroleptic medication is most effective and used to slow or stop the disease process (Loebel *et al.*, 1992).

A residual phase may be marked by low level psychotic symptoms. Generally, the negative symptoms of schizophrenia are more difficult to treat and persist through the residual phase, which is also characterised by role impairment.

The relapse prodromal indicates the potential for relapse by the exhibition of unusual behaviour. Relapse prodromes are shorter in duration than the initial prodrome. If a definite diagnosis of schizophrenia has already been made, then relapse prodromes may be easier to spot. Early intervention may prevent relapse (Herz and Lamberti, 1996). It is in this phase that unusual behaviour is most problematic since not only are there no adequate measures against which to gauge usual behaviours against unusual ones, but what unusual behaviours could possibly mean after the diagnosis of schizophrenia and between schizophrenics themselves remains equally uncertain.

The course of schizophrenia can follow different trajectories. Each phase differs in duration depending on the individual afflicted. Generally however, male schizophrenics enter the psychotic phase between 17 and 30 years of age and females between 20 to 40 years of age. In 5% to 15% of patients, psychosis is continuous. Problematic in the course of schizophrenia is the notion of a cure. More and more it seems that 30% is accepted as

the percentage of those cured (approximately half of this number still having some residual symptoms). Workers at drop-in centres regularly cited 5%. It is interesting to note that clinically, patients who are no longer seeing a psychiatrist are generally regarded as having been successfully treated. For the centres' staffs however, getting users to come back daily was the success and those that did not return at least regularly were thought to be deteriorating. Aside from a percentage of schizophrenics who do seem to be cured and have no "residual" symptoms, the residual and relapse prodromal phases remain unclear as conceptualisations of remission versus cure.

What causes schizophrenia is unknown. Its variability and mosaic of symptoms even lead some to suggest that it is not one disease but several. Nonetheless, schizophrenia is a diagnosis with the dire consequences of the stigmatisation of mental illness. According to the World Psychiatric Association, half of surveyed Canadians confused schizophrenia with split personality disorder. Half of those surveyed would neither marry nor share an apartment with a schizophrenic and more than one-third have no idea what causes it (Gadd, 1997). A survey for Janssen Pharmaceuticals in the United States indicated that people associated split personality, multiple personality, insanity and violence as symptomatic of schizophrenia. The same study also showed that respondents believed drug abuse, social environment, a nervous breakdown, poor parenting, weak willpower, laziness and/or idleness to be causes of schizophrenia (in USA Today Magazine, Dec. 1997).

Beyond a diagnosis is schizophrenia as a situation and circumstance involving homelessness, under-employment, poverty, marginality, voicelessness, abuse and neglect. Seven percent of homeless people are schizophrenic according to statistics by the Clarke Institute (Clarke Institute, 1998). Only approximately 15% to 25% of diagnosed schizophrenics can do some sort of work (Nichols *et al.*, 1995: 72; Rheinstein, 1999) and according to Maclean's Magazine, 4% of all inmates in Canada are schizophrenic (Nichols *et al.*, 1995: 72). As a narrative, schizophrenia is infused with psychiatric jargon about the rupture of peoples' lives as they struggle to hold things together while dreams are being

eroded and relationships are falling apart. Above all however, schizophrenia is about people, those afflicted, their family, friends and caregivers. Different ways of mapping out schizophrenia illustrate the multiple perspectives from which schizophrenia may be viewed. This is not about differences within the symptomology or manifestation of the illness/disease nor is it about statistical (age, gender) differences between schizophrenics. Instead, it is a reconceptualisation of an illness/disease that may allow for the clinical observations of schizophrenic symptoms to be overlaid on the life of the individual through an understanding of phases, themselves part of the life of the individual.

Explaining disease in strictly biological terms fails to account for how the longevity of dysfunction is itself part of the disease. How the experience of being ill may figure into the symptomology of the disease is one point that may allow for the intervention of other (non-medical) disciplines. This also grants the opportunity for the schizophrenic as an individual (a post-modern subject) to express the illness rather than merely being its carrier. Schizophrenia is, after all, manifest differently in each individual. There are alternative ways to view schizophrenia that allow for intersubjectivity within a medical model. A pathology of common sense is one such understanding of schizophrenia removed from the technical, psychiatric disease model. It is also possible to re-introduce the schizophrenic back into a discussion of schizophrenia directly by superimposing his/her life over that of the course of schizophrenia. The five phases of the course of schizophrenia show how the symptoms of a disease may be overlaid with the experience of schizophrenia as a subjectively experienced illness. Moving beyond organic brain dysfunction, disease, can be the clinical validation of an illness. Subjectively experienced illness is combined with other upsets and problems associated with disability, marginalisation and alienation among other things.

## Chapter 6 - The Field

This chapter deals with the field as the site for the work of this thesis. Asylums are not simply closed creating a void. In the wake of institutions there exists networks on the outside on which the schizophrenic may rely. Community-based centres, drop-ins, bed-sits and missions are the pillars of one such network. How schizophrenics use this network to their advantage, construct a web of social networks and meet needs for shelter and food is part of an ongoing process mediated by the staffs at these places, their resources and the demands of other clients. This chapter looks at some of these places where such networks are created.

After deinstitutionalisation, many of the places to which schizophrenics are forced to turn are, for them, initially only instrumental. Opening hours, the time and type of meals served and other services provided are the primary motivation for going to one place rather than another. Most places however do have their own ambience and way of doing things to which the users become accustomed and which eventually figure into how they decide where to go. In addition, these places are central sites for socialising.

As noted earlier, Quebec is the only province with a system of community-based clinics. These clinics are for many schizophrenics essential for maintaining good mental health. For others, they are burdensome and visits to them are chores to be avoided. Only one informant expressed closeness with her psychiatrist. The others understood their relationships to the staffs at these clinics as clients (or "consumers of mental health services") only. These clinics are also intertwined with procedures and protocols that make personal relationships difficult. As much as Shelly felt close to her psychiatrist, she had no choice but to accept another when the former was shifted to another institution.

At the other end of the spectrum of deinstitutionalised services, there were drop-in centres where the users were members and all knew one another's name. Members could

ask (and then hope for) specific meals to be provided and the staff members could, as friends, extend favours. Special among these was loaning money.

Somewhere between these two images, there were the missions and residencies. Lots of users coming and going, staying for the night, a week, one month or several often meant that people moved just as they seemed to be establishing relationships. While these places were highly organised with staff working on a tight schedule to arrange the beds and dinners they were also the places where friends met at the end of the day and where, occasionally, best friends lived just down the hall.

Shelters and residences were gendered spaces. Many community spaces are not open to both genders: gender determines access to certain spaces services and networks. In addition to the mixed spaces of soup kitchens and drop-ins, women have recourse to women's shelters, which in turn are usually geared towards addressing problems of spouse abuse and rape.

### *The Centres Locaux pour les Services Communautaires*

Services provided by the CLSCs are referred to as "first line care" (gov.qc (d), 1999). After the *virage* and several amalgamations, there are 26 CLSCs. One is private and three are run by chronic care hospitals. The government web page states the following CLSC mandate:

The mission of a CLSC is to offer basic health and social services of a preventive or curative nature and rehabilitation or reintegration services to the population of the territory that it serves. It must see to it that the services required are offered, according to need, in its facilities, in the clients environment, in school, in work or at home or, where necessary, refer the persons to the resources best suited to assist them.

All CLSCs have the resources for offering in-home care and services to the elderly with reduced independence and physicians available for patient consultations either on a walk-in or appointment basis. [...] There are also childhood, youth and family programs as well as programs focusing on specific client needs such as mental health and AIDS screening, including psychosocial support to ensure that the affected individuals receive services, suited to their needs in a perspective of prevention, promotion of health and well-being. CLSCs are distinctive in that they offer a range of health services and responds to needs not requiring the specialized treatment or equipment that could be found in hospitals or ambulatory care facilities (gov.qc (d), 1999).



Although little research included in this thesis involved any CLSCs this is a useful point to begin descriptions of community-based centres as physical places. On one hand CLSCs are important locales for some schizophrenics to gain access to services and for community centre staffs they are an important source of resources. On the other hand however, as physical places the CLSCs were unimportant for most of the people interviewed and indeed, places perceived either as too difficult to get to and too fraught with bureaucracy or to be outright avoided for personal as well practical reasons. There is however a "homeless team," consisting of nurses, psychiatrists and a social worker operating out of one CLSC. Because they cannot adequately treat patients in the centres which they visit, they usually offer the best care they can provide on the spot and make appointments for people during regular CLSC hours. The social worker on the team informed me that few of the users of the outreach ever show up at the CLSC. Nonetheless, this team is a major link to CLSC services for centre users and workers alike.

CLSCs appear to the user as a regular business. They operate during regular business hours and the buildings they are located in look like offices. They are generally well situated near main transit routes in mixed-use neighbourhoods. Although CLSCs are responsible for a catchment area, many services are increasingly centralised especially those geared towards mental health services consumers. In addition the CLSCs are undergoing amalgamations increasing the size of their catchment areas and increasing the workload of workers. Generally, services are meant to target a population in a specific geography. Some smaller CLSCs are not adequately able to provide English services.

Accessing CLSCs often requires going through several "gate keepers." Usually one is required to pass by a receptionist at the entrance of the building, before moving on to some sort of a triage nurse/receptionist then waiting to see a doctor or other professional. There may also be various security measures such as needing staff (a professional) to be escorted to the offices, through a locked door requiring an access code.

## The St. Thomas

Contrasted to this image is the one of a drop-in centre, particularly one known to serve food at regular hours. In 1985 the Saint Thomas Drop-in opened. It is located in the rear of a church. The congregation of the church decided to do something about the people who were wandering in off the street looking for help, clothing and food. Eventually, the drop-in adopted a mandate to care for the mentally ill. Because there are more demands being made on its resources than it can meet, the drop-in has devised a sort of membership for its users. Although they still assist people coming in off the street this now takes the form of guiding them to other resources. A social worker at the St. Thomas explained:

Even if it was physically possible for to get more people here, to cope with more or have more staff, we need to limit the amount of users. People who need to come here need a [...] personalised service. They need to feel at home [...] to have a sense of familiarity.

On my first visit to the centre, people were celebrating one of the users having given birth. Workers were calling other centres in an effort to find diapers, baby food and other items for the baby.

Funding is difficult for the centre. With three social workers and two assistants, the centre operates with a budget of \$140,000. Usually one of the users works at the centre as part of the Extra programme under which they are able to supplement their welfare. During the academic year there are also social work students fulfilling internship ("stages") requirements. There used to be only two social workers and one assistant but the others were needed and hired after the provincial government boosted funding. At the same time however the municipal government cut its grant in half (Derfel, 1996a: A6). Some support as charity is offered by individual members of the congregation although there have been clashes with the church. The church has a lot of vacant room but the space occupied by the centre is also used by other groups. Alcoholics Anonymous for example, after the centre closes. Once the space was used to shoot scenes for a television series and the drop-in used another space in the church. Conversations with centre staff here and in other church

located centres, left the impression that although the churches were committed to charity works, they were unprepared for many of the other "problems" associated with homeless and mentally ill people, such as people "loitering" on the churches' lawns during the summer.

Success for the centre staff is hard to gauge but one measure seems to be the rapport they have with the users of the drop-in. Having the users come back is not only an opportunity for the staff to stay in touch and make sure that things are going alright, but indicate that the users feel comfortable and at ease asking for help. One third of the people using the St. Thomas Drop-in have no fixed address. Whereas in the early 1990's, staff coped with an average of thirty people daily, they now meet the needs of between 60 and 80 people during operating hours from 11 AM to 6 PM (Dertel, 1999a: A6).

The St. Thomas is located on the top of three floors behind the church. It shares its entrances with the church's offices on the second floor and usually one of the staff stood by the door during peak (dinner) hours to make sure that no one wandered the halls or entered the other rooms and offices. There is some sort of hall and kitchen in the basement but this area is usually locked, accessed by staff who use the laundry facilities there.

There are several rooms that the drop-in centre uses for storage and one office that is usually open for anyone to use the phone but which also offers a place for private talks with staff. The main room is like a loft at the end of a hallway. It is wide open, ideal for keeping an eye out on everyone. A counter in one corner surrounds the kitchen area. There are several chairs but most are stacked when not in use. There are couches along the walls where people sleep during the day, two or three long tables, an upright piano and an old floor model television that is the centre of entertainment. There is also a small radio in the kitchen and the counter top is invariably littered with snacks. There is always tea either made or being made. For dinner the area is dominated by tables, as many as are needed. Practically, the best features of the room are the windows and the door to the fire escape. These offer ventilation and a separate entrance/exit in the summer. There were paintings and

drawings on the walls by the users and plaques with what I initially understood to be Christian adages<sup>11</sup> but later associated with more specifically with inspiration for alcoholics in the twelve-step programme. Most striking about the room however is that feeling of being in someplace once magnificent as insinuated by the high, domed ceiling.

This drop-in allows smoking and even with the windows and door open, the air is thick and seems trapped in the dome. The main source of food is Montreal Harvest which provides to drop-ins and food banks the food that retailers no longer think fit to sell. During the summer they seem to have more from farmers' markets. Meals then depend on what is available. Sometimes there was a stew, other times cheese and macaroni or something else. The staff always attempted to produce balanced meals usually incorporating a salad. For users, what the meal would be (as opposed to just eating or even the centre itself) was a key reason to make one's way someplace else where, hopefully, the meal would be more to one's liking.

Unlike the "first line care" of the CLSCs, the St. Thomas is initially striking as chaotic. There was not the sense of order and the regulated flow of people nor were there definitive roles being played. The staff at the St. Thomas wore casual clothes and were difficult to pick out, especially among the users who claimed to be, and acted as if they were, in charge. The smoke-heavy air and a feeling of uncleanness added to a sense that there was no control. There was also a desperate sense of passing time, waiting for an event that usually turned out to be dinner. About his visit to the St. Thomas, Derfel wrote.

A man wearing a black cowboy hat is mopping the floor in a room crowded with the mentally ill. [...] The man is making himself useful, but most of the people sit listlessly watching the Rosie O'Donell Show on TV or pace back and forth mumbling to themselves. A couple of men play a board game, while a woman sleeps in her winter coat on a mattress in the corner (Derfel, 1999a: A6).

This description conjures up many of my feelings from when I visited. There was a complacency in a circumstance that didn't seem to offer room for complacency and a sort

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<sup>11</sup> Adages such as, "Lord give me the courage to change the things I can, the strength to accept those I cannot and the wisdom to tell the difference."

of listless motion. Peoples' identities were more similar for having been there – watching television, eating – than dissimilar for why they were there – drug problems, homelessness, and psychiatric illnesses.

Although the distinctions between a CLSC and a place like the St. Thomas are sharp, in all fairness, they are not meant to provide the same services or *milieux*. The success of the St. Thomas is its relaxed atmosphere and non-judgmental tone and for the users, who is in charge and to whom one needs to turn for help is indeed marked by their professionalism and not their a uniform. Despite this though, it must also be noted as Derfel does that “the staff are assuming more administrative tasks that used to be handled by the hospitals, like filling prescriptions” (Derfel, 1999b).

The St. Thomas drop-in centre closes for the month of August.

### **The Blue Barn**

Another centre close to the St. Thomas and also run out of a church is the Blue Barn. The Blue Barn opens in the morning and serves peanut butter sandwiches for breakfast. Tea and coffee are available until closing time at one o'clock in the afternoon and there is always bread. Lunch is soup and usually a desert of doughnuts or some sort of pastry. The soup is prepared daily and is made of what is available: meat in the soup is a rare and exciting for the users here. Meals are served on a first come, first serve basis and despite the long line-ups there is usually enough for second and third helpings for those who arrived on time. Coffee generally is a rarity in drop-ins especially “all-you-can drink.” Coffee was one of the biggest budget items for the centre. There is usually some pop and juice. Food that doesn't go into the soup (e.g. lettuce, fruits) is set out for users to help themselves to. The Montreal Gazette also donates papers daily. Most users seemed to find the paper entertaining with its comics and crossword. Few read the employment pages.

The Blue Barn has fewer resources than the St. Thomas and fewer rules. No one is ever banned from here for more than a few hours or the day. If the St. Thomas is non-judgmental, then the Blue Barn is no-questions. Intimating this is the amount of sugar

they use in pre-mixing some of the coffee. Lots of sugar, as one worker told me, helps some users cope as they come off their (recreational) drug high. The social worker here said he didn't believe in barring people and expressed a philosophy that as a social worker was an advocate for social change and complained that other centres were too bogged with administrative tasks to remain truly dedicated to their clientele. He was, for instance, disheartened that the St. Thomas closed for a month's vacation in the summer.

The total number of lunches served corresponds to the number of users at this centre. Generally there are fewer users at the beginning of the month and numbers build steadily until monthly cheques are received such as welfare. Two people staff this centre, one of whom is a social worker. There is also usually at least one volunteer although this centre has been less successful in attracting internees than other centres.

**Number of lunches served for the months of April and May (1997) at the Blue Barn.**

	Mon.	Tues.	Wed.	Thurs.	Fri.
<b>week 1</b>		48	59	59	73
<b>week 2</b>	88	92	93	100	78
<b>week 3</b>	91	89	90	105	68
<b>week 4</b>	117	110	100	116	111
<b>week 5</b>	100	83	73	46	54
<b>week 6</b>	76	74	75	94	98
<b>week 7</b>	108	101	100	95	95
<b>week 8</b>	<i>Holiday</i>	109	106	104	84
<b>week 9</b>	110	97	88	42	36

Unlike the St. Thomas, this centre limits its focus to feeding and providing a safe place for whoever comes through the door. This centre closes only on the weekends and statutory holidays. Because this centre opens earlier than the St. Thomas, there are a lot of St. Thomas' regulars here who would later

move on to the St. Thomas. There were more young people at the Blue Barn than at the St. Thomas which likely had to do with the membership requirements of the St. Thomas. Sometimes the users at the Blue Barn were visitors to the city, on a budget and perhaps staying at a hostel. The Blue Barn staff, although they knew the vast majority of users, did not seem to have the depth of relationships with their users that the closed membership of the St. Thomas afforded. However, their few rules and no barring principal meant that they were able to reach those who had had other contacts severed.

Space-wise the main area was laid out like a cafeteria with tables running parallel to the entrance. The Blue Barn had recently been renovated so the place looked new. Again there was an upright piano and television in addition to a stocked bookcase. Although there were two washrooms, one had the washing machine and dryer sharing its space and was reserved for staff. The other washroom had showers and urinals but sometimes one of the few women using the centre would use this washroom. If a woman needed to use the washroom, especially to shower, men would have to wait until she was done. Once while I was there though, a woman just walked in and used the toilet and sink. Separating the kitchen and this washroom is window so that the staff can keep an eye on everyone in the washroom. This drop-in also dispensed toiletries. Disposable razors and dollops of shaving cream were in high demand.

The kitchen was separated from the main room by a sort of walled-in counter top. One could look across the counter into the main room but there was part of a wall that made the kitchen seem to have a semi-private area. Some users came into the kitchen but very few and even fewer passed further than a meter beyond the threshold. Most came to use the wall phone although usually the staff would be asked to dial a number and the user would pick up a handset extension mounted outside the kitchen. Off the kitchen was a large pantry type of area and the kitchen itself had new, industrial appliances. There was a radio for staff.

Past the main room there was also a secure storage area for users who needed to stow their things for a few days. There were also more pantry areas and a large room where cloths were neatly arranged. Twice a week for a few hours this area was opened by one of the volunteers so that users could pick out clothes. Socks and shoes were much sought-after items. Occasionally, staff would allow a known user to do his laundry using the machines there.

Occasionally the Blue Barn gave out transit tickets. Users constantly asked for them but since they were bought (at full price) rather than donated, tickets were a rare commodity.

The Blue Barn, being one of the first places to open in the morning also offered a safe refuge for those who had stayed up all night. Many people did not come for the meal but simply wanted a place to lie down for a few hours.

This centre also had art classes for its users and paintings were on the walls. In addition there was a display case fixed to the half-wall separating the kitchen from the main room in which miniature sculptures made by the users were on display. The Blue Roof, because of fire codes and bylaws, cannot allow smoking inside. People smoke either just outside the entrance or on the church's front lawn.

### **The Old Carling Mission**

Different from these centres which reach their peak during the day and draw people in primarily by offering food, missions and shelters attract itinerant people in the evening and although they might offer dinners, their main attraction is a bed for the night. Places such as these have larger staffs (kitchen and cleaning staff) than drop-in centres and more administrative tasks. In some places, beds have to be reserved early in the day. Twice a year, those without a permanent address are eligible for welfare after spending three nights consecutively in a mission or shelter.

The Old Carling Mission has several hundred beds split between three locations: two for men and one for women<sup>12</sup>. The mission runs a shuttle bus to move people to the different locations. For the men this means that overcrowding is eased. Derfel states, "The staff regularly dispense anti-convulsants and anti-psychotics, even though they know very little about these medications" (Derfel 1999b: A6).

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<sup>12</sup> The new women's shelter is new building and after some delay finally opened in 1998 several months after the research was completed.



The space is very large with several floors. It was also very clean. There were large dormitories, some private rooms, recreational areas and a sort of detox room with padded walls and mattresses on the floor so that users could not harm themselves. Staff stressed that they did not turn people away although they cannot accommodate minors.

There were always line-ups for meals which were served in a large cafeteria like setting with a fully staffed cafeteria kitchen. It seemed that at the one location people left soon after eating although it was unclear if they left to be on their own or were being shuttled to another location. However, at least once a week, a social worker and nurse visit as part of an outreach programme and many people stayed for a check-up. Visits with the outreach team were held in the mission's office for privacy.

Users who spend the night are required to shower. In addition to a shower attendant, there are also cameras throughout the building. The Old Carling Mission seems impressive with its large capacity, cleanness and security. In contrast, Jimmy who used the mission while he was down on his luck had a range of complaints. He believed that two workers in the kitchen were HIV positive and was shocked that no one wore rubber gloves. He complained that the mission did not provide a pillowcase, that the beds were uncomfortable and that showering was ineffective without a clean change of clothes. Jimmy thought the meals could be better and he hated having uncomfortable sleeps with "stinking people."

Because shelters were gender sensitive spaces, I was only able to visit the women's mission once. I went with the outreach team and my visit was limited to the main room and the office. A description of the place in light of the fact that the facility has moved into a new building seems futile. More than anything else however, one thing sticks out in my mind and that is the warning from the outreach team that the women in missions were worse than the men and had relatively more severe psychoses. My impression of the people there, after having been tainted, was nonetheless that they were more troubled than the men in missions were. There was a lot of yelling, at each other or at no one at all, and there were a

few fights, hard and quick. Generally, homeless shelters gave insight into what other personal and socio-political problems were being blended together and in the process confused with mental illness (e.g., unemployment). Women's shelters added to this list of intersecting vectors such things as spouse abuse, rape and assault.

### **The White Shield**

Like most other major urban centres, Montreal has an established link to several large charitable organisations that operate a network of thrift stores, homes and residences. The White Shield is one such organisation. During my research, the White Shield had begun to charge five dollars for a one night's stay in the dormitory, including breakfast. There was also a residence where one could rent a room, have meals provided and share common areas and facilities. Long term residents paid each month a percentage (75%) of their income (social assistance payments) for room and board. The one men's residence I spent time observing in was an older building rather like a school made of cement painted in disturbing orange and yellow colours. There was security to pass by and one had to be buzzed through a locked door by guards. The White Shield was uncomfortable with its long corridors, small rooms and single cramped elevator. The residents seldom left the White Shield. Despite stating how much they valued their freedom, they spent most of their days in a common room. Here there was one television mounted to the ceiling. It was always set to one station for the day. Residents seemed to have places they always sat. In the common room I often saw men who looked to have been severely beaten. Some had bruises and cuts healing while others had long since coped with parts of their faces having been crushed. One of my colleagues would comment that the White Shield physically resembled a prison. My impression was that it like a warehouse. Space was minimal and Spartan with no aesthetic appeal but more than that it seemed as though people were simply being stored there. Despite my impression that few people exercised in and out privileges or other freedoms, one resident, Laurent again, stated:

**The freedom we're given is SO broad. [...] It's the first time I saw a service so open. I mean to the point of respecting the liberty of individuals**

[...] to leave them quite free in fact.

When asked what he did with his freedom he responded, "I'm not a good example. I sleep a lot."

As with other missions, staff dispensed medications. At the White Shield, one office had its desk and filing cabinets littered with small jars of pills. My understanding was since the White Shield controlled the residents' money and meals, that it could ensure that they took their medication and followed their regime. But as one informant, Carlo, who went off and on his medication clearly illustrated, accepting the dispensed medications and actually ingesting them were two totally different things.

The residence shares the building with the dormitory as well as other wards on different floors meeting different needs, such as the detox ward.

Faced with a limited budget the White Shield cannot afford high wages and one (seemingly disgruntled although not vindictive) employee said, pays minimum wage. As a curiosity however, several of the staff were trained, skilled professionals who had immigrated to Canada but not been re-licensed to practise their skills here. This was most evidently the case with a "doctor" who was not licensed here but had been an army doctor in the USSR. Although the situation of this ex-military doctor was extraordinary, many residences such as this one were run as though they were part of the military. Personal with military backgrounds were common and some places had adopted a military hierarchy with generals and colonels.

The employee expressed concern not only about the level of care and dedication to work that minimum wage inspires, but the mixing of different populations as they were allowed to move between floors. He told stories of other users attacking and robbing the elderly residents. Coincidentally, a social worker had observed that several older people in residences and in missions were there because they owed all their money to bookies, loan sharks and other "Shylocks" who regularly beat up their debtors. The White Shield was rumoured to be reluctant to involve outsiders such as the police, Urgence Santé or even

outside social workers and psychiatrists for fear that they would be able to have some (paying) residents removed. It was also rumoured that the White Shield preferred the mentally ill as residents because since they charged a percentage of income, it was more profitable to those whose social assistance was augmented. Reluctance to involve the police was one of the employee's complaints. Some students of social work were completing their stages there. It also makes sense that in many cases, augmented social assistance is an indicator that greater care is needed and adopting a payment based on a percentage of social assistance is a way of charging for this needed care as the increased social assistance anticipates that need.

All the residents interviewed from the White Shield seemed happy to be there or complacent. Since for most this was the first stop after coming out of a hospital or prison, their happiness has to be assessed relatively. There was though, a sense of people mingling if not community, at least for some. Best friends lived on the same floor, groups of friends hung out in the common room together at the same hours and sharing (especially cigarettes) was a sign of camaraderie. Indeed for many this was the only place where they spoke of living out their lives. Others appreciated just the meals and laundry facilities.

While on the rounds with the outreach team, a social worker commented that although one would expect the shelters and missions to be full at the end of the month and during the winter, in his experience, how full the places were was fickle. At the St. Thomas there were several people who were known to bounce between staying with different friends and using the missions: some preferred living on the street all year. Dunkin' Donuts and all night coffee shops were also favourite places for the itinerant. There were also stories of weeklong drinking binges<sup>13</sup> without sleep.

What this general description of specific places does not provide is of course any description of the spaces between them. Schizophrenia is not limited to a social geography

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<sup>13</sup> Anecdotally, one man with only his thumbs was known to have lost his fingers after passing out in a snow bank in the middle of winter after a drinking binge.

and schizophrenics have to move through and navigate the city well. Not only are they forced to move as part of exercising choice (finding the most appealing meal) but also just to access services. Getting to the appropriate CLSC is difficult without money to pay for even public transit and making it there during regular operating hours may prove impossible if one has to negotiate reserving a bed for the night and getting meals at the same time. The logistics of being somewhere at a certain time for the best services and then somewhere else for the best bed while place and time are non-negotiable in many ways made for the worst possible scenario in which to organise a day. Services are scattered throughout the city and the city itself has a large geography. Severe winters make even short walks difficult and unpleasant. At centres that distributed clothing, socks and shoes were coveted items. The most common ailments that the nurses on the outreach team dealt with involved the feet and such things as severe blisters and frostbite.

This chapter was mainly intended to provide a glance into what the spaces are like that schizophrenics move in and between: the social networks forged in these spaces and the political climate that has created and maintains these spaces. Holding all this together and making it somewhat more familiar are the users that move to and around these different spaces. Some users had more of a circuit than others did. An example of a circuit could be sleeping at the Old Carling Mission, having breakfast at the Blue Barn, spending some time in a mall or on the street, moving to the St. Thomas for dinner and then back to the Old Carling.

Going through this circuit with other users often formed bonds even if those users only recognised each other but rarely spoke. Users of the St. Thomas usually stayed together at tables during breakfast at the Blue Barn. A sense of solidarity among users was retold to me in the story of Bobby as recounted by one user of a drop-in.

#### **Bobby's Story as Expressing Solidarity**

Bobby was in his mid thirties and mentally handicapped. He functioned like "an eight year old boy." He was friendly and loved to talk to people. He wasn't really a user

of the drop-ins or the mission because he stayed in an open, special care home. During the day he preferred to wander the streets and would often come to the drop-ins during mealtimes to chat with his street friends there. Some of the users of a drop-in learned that a taxi driver had been bribing Bobby with candy to get Bobby to perform oral sex on him in the back of his cab.

We got together a few other guys from --- and beat the shit out of the cabby. He was laid up in the hospital for a long time man. But that was the end of it. Yeah we look after our own...

This story shows that drop-in centre users and the homeless had a sense of community built out of a seemingly fragmented, isolated life of marginalisation on the street.

There are of course many more drop-ins, missions and shelters in Montreal. Some were only as large as a walk in closet. Some of them cater to particular ethnicities others to age groups. None are without rules and all are highly organised spaces with codes and systems of governing. Vestiges of religious philanthropy, they each have their own relationship to volunteers, charities and government funding. Many had social workers on staff, none had their own full-time psychiatrist and although I think workers provided valuable services, these were not places for therapy.

Learning the rules of a dozen centres and using them during their operating hours requires a certain amount of savvy. The centres described above are having their roles stretched and redefined amid the *virage*. More mentally ill users and increased responsibility for managing drugs are just the tip of the deinstitutionalisation iceberg. These places, their users and staffs are the most evident result of the retreat of professional psychiatric care and the pre-eminence of public policy. The centres and their staffs are the new network of mental-health care providers, etching out new roles and relationships with their users/clientele.

## Chapter 7 - Some Lives

Human action creates the story for which narrative provides the essential form of understanding (Barham, 1984: 61). What schizophrenics do is the actions which when narrated offer a particular insight into what it is to live with schizophrenia. In the following pages, four life histories pieced together from a series of interviews conducted with informants are presented. The stories they tell explain what the consequences, in terms of their lives, are of a diagnosis.

Both the medical definition of schizophrenia and the course of schizophrenia are concerned with disease pathology and its manifestation in terms of illness and symptoms. The course of schizophrenia and its presentation are both, "characterised by islands of normality surrounded by oceans of chaos, with bewildering variability between patients" (Johnson, 1992: 98). This variability between patients occurs in symptomology as well as in different opportunities lost and gained by the post-diagnosed schizophrenic. For this reason it is important not to forget the individual. To this end here is a sampling of various life histories. These life histories have been subject to many interjections but mainly with the goal of improving flow. For the most part, commentary and asides have been avoided<sup>14</sup>.

Of the following four informants three are black and immigrated to Canada some time ago. The other is of Greek descent. This thesis is not about racism and the stories presented here were chosen for their completeness and because in many ways they were typical of other stories. But, this research is rather limited in scale and as such I would not propose that these stories statistically represent a sample from which a population could be extrapolated. The three black informants' stories were particularly rich because when these informants were encountered they were very approachable and spoke a lot, providing some

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<sup>14</sup> These particular stories were selected because of their relative completeness. However, because contact with my informants was mediated by centres' staffs, few of the interviews (none presented here) involved anyone with florid symptoms -- that is no one was psychotic. Not only then do these particular life

of the most complete life histories that the research collected. They are also well known by other users and/or workers, who also spoke of them. In addition one informant had a brother, Richard, who was also schizophrenic and a close friend of another one of the informants. Richard's life history was difficult to access and remains incomplete mainly because he preferred to speak about the other users of community centres in general. More than providing a lot of information about himself though, he filled in several blanks about others. In the telling of two of the following stories then, there are three narrators with their lives overlapping more so than just in the social space of the centres providing an opportunity for different perspectives and insight into each other's history. The third black participant selected for this section is unknown to anyone outside of the residence where he lived. His story is the most complete one obtained during the research but it is also the most difficult to follow. Of course, each schizophrenic's life story is unique and even in using these to illustrate the course of schizophrenia, they are not offered as a metanarrative, but rather as offering realistic illustrations that although not common, share commonalities with most of the schizophrenics I encountered. Primarily, these narratives should be seen as "keys to the personal meaning of illness [schizophrenia] and the historical, cultural and institutional shaping of that experience" (Lovell 1997: 355).

## **Glen**

The first informant, Glen is Greek Canadian. His story is relatively short and yet in many ways is typical of many users of a drop-in. He has spent time in jail where his diagnosis occurred and has a drug problem (albeit a severe one). What is interesting in Glen's story is that he has a high degree of functionality yet has to rely on the drop-in mainly for reasons other than his schizophrenia. His drug addiction problem increases his marginality and limits his options.

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histories tell the stories of particular people but of particular schizophrenics at a specific point in their disease.



Glen was 36 at the time of his interview in 1997. For him schizophrenia means that he hears voices. Arrested for armed robbery in 1987 he was diagnosed in prison as schizophrenic. Glen said he hadn't heard any voices until about three years before this point. He had a normal life, which made his diagnosis initially difficult to accept. About the psychiatrist you evaluated him:

I didn't believe him the first time. 'Cause I used to work. I had a girlfriend. I was engaged and everything broke loose. you know?

Upon his release, part of his probation included the requirement that he keep up with his medication. Now off probation, he continues with his medication for most of the week. The drop-in centre he uses administers his medications. Although they are only pills (four pills a day), Glen does not self-medicate. Even though his regime requires him to take medication daily, he leaves the centre early on Fridays before medications are dispensed and does not take his medications on the weekends when the centre is closed. Glen did not feel that missing a few days every week effected him since he always returned to the regime on Mondays.

For Glen, his diagnosis helped him. "I don't hear voices. It's been three years. I don't hear voices." More revealing of the utility of the diagnosis however, is that Glen, on welfare since leaving jail was able to augment his benefits because of his diagnosis. He has had a cocaine problem for several years and he signs over his benefit cheques to the janitor in his building who then pays his rent and supplies him with cocaine. Glen panhandles for money and cigarettes. Although he is able to live in a shared apartment, he needs the drop-in to provide food. He also showers at the centre since his budget, spent entirely on drugs, doesn't allow for soap at home. Staff are not equipped to deal with his drug addiction and as long as he does not act out in the centre, he is welcome to use its services. Since the centre is the only thing keeping him on his medications, not having him come would be a failure.

Glen was the only informant who was at the drop-in everyday for most of the day. Not only did Glen not cook or wash at home, he was unconcerned about where he did eat

and shower. In this way, he was unlike other users who moved between places in order to get the best possible services. Glen was only concerned with feeding his drug addiction. In this way, eating, showering and socialising were the spaces between events (taking drugs). This is in contrast to how grooming, eating and socialising were the main events of other users' days.

Glen's drug addiction problem presents one fairly consistent problem among drop-in centre users. One worker at a mission spoke of medicated users attempting to sell their drugs. Although this may simply be an effort to raise money it reveals how blurry the line between pharmaceutical and recreational drugs may become. The distinction separating psychiatric drug culture/treatment from street drug culture may be only of legitimisation and authority. More than likely however, it was the populations at drop-ins that perpetuate addiction among users. Drug users and drug sellers shared a space that also subsidised their marginal lives, enabling them to pay for their drugs and alcohol which furnished their escapes.

At the end of the research nothing had changed for Glen. He had not moved, conquered his addiction nor stopped spending his weekdays at the drop-in.

### **Michael**

When I first met Michael in 1996, he was 38 years old, very talkative and easy going. As we got to know one other I understood a certain charisma he had that allowed him a lot of leeway in his dealing with other centre users and staff. He liked to kid around with everyone and for the women always tried to keep up a sort of sexual banter. Michael emigrated from the Caribbean through Toronto more than twenty years ago. He lived with his mother for a while before attempting to strike out on his own. All he wanted to do was work and eventually a friend landed him a job at a fast food restaurant. He lost that job after punching a time card for the same friend that got him the job. From here, his narrative is mostly of being homeless.

For Michael, Toronto was too busy and overwhelmed him although he recognises that he had a better chance of getting a job there. Michael learned some French in school but never achieved fluency. Nowadays he says he has times when he remembers his schooling and can converse in French but others when he can't understand a word. "I'm pretty good at it sometimes. Sometimes I lose it. You could be talking to me and I don't know what you're saying no more, in French." Michael seems to have constant struggles with drugs. He admits to smoking marijuana but a lot of his struggles involve resisting harder drugs. The prevalence of drugs is indicative of his situation as a poor man who uses drop-in centres and his resolve to resist them shows a dedication to his family, especially his daughter, who was just one year old at the time of our first meeting in 1996.

Michael was arrested for selling drugs to an undercover police officer. This event marks his diagnosis as schizophrenic. Encounters with the law are common among schizophrenics and Michael is no exception. He claims a record of 14 arrests for several petty crimes mostly shoplifting which incidentally he excused as him having been overwhelmed by the wealth of Canada, and wanting some for himself. Relative poverty has followed Michael and plagued his life here in Canada where he feels himself better off than back home yet still poor relative to other Canadians. "Financially I'm trapped ... No way I can make a dollar unless I go steal or thief or do something like that."

Michael's friend, however, questioned Michael's resolve to work and criticised him for never really wanting legitimate work. Richard implied that Michael's greatest saviour is the welfare state.

In any case Michael's diagnosis was made while incarcerated for selling drugs. Another incident however seems to have sharpened his awareness of having schizophrenia. Again this involved the police.

I was lying down in the grass sleeping, you know, and all of a sudden the cops put handcuffs on me and tell me I just snatch a woman's purse. I told them I didn't do it. I have no money I have nothing ... They carry me to jail ... I end up getting a year in prison.

For his part Michael says he didn't snatch the purse or at the very most, doesn't remember. Although Michael would have preferred to not have been sentenced, he also sees this as the point when he was able to get help. Help is multifaceted in this sense. The arrest solved his problem of homelessness, while his diagnosis diverted him away from other inmates into the more tolerable space of the psychiatric ward.

Initially, Michael did not believe his diagnosis because he had never before heard of schizophrenia. "I didn't know there was schizophrenia until I was in Montreal." Understanding what schizophrenia is was essential for him to accept his diagnosis. Particularly, it offered him an explanation for the voices he heard in his head. The voices, which Michael remembers having had back in the Caribbean indicate for Michael that he has had schizophrenia for a long time, before coming to Montreal. Diagnosis back home wasn't possible because there "[they] didn't have the doctors and things to tell me." His understanding of what schizophrenia is not as clinical as it is pragmatic. Not only does it augment his welfare benefit, but also, having had problems with immigration, Michael feels that his diagnosis helped in his bid to stay in Canada. Being on a medical regime, with which he is compliant, is a way for him to prove his responsibility. Meeting appointments to get his medications every two weeks, is an example of this responsibility. Days when he has appointments for his injections motivate him and allow him to prove his organising skills. "When I know it's for the shot, man I'm up at six o'clock in the morning for that."

Michael like most other schizophrenic informants did go off his medication for periods of time. Although I suspect that he had a variety of reasons for doing so, his most compelling was that one of the side effects was impotency. I assume that this was a strain for his marriage. Seeing how much of Michael's personality and charm was predicated on sensuality, impotency must have also put his biology intolerably out of sync with his personality.

When Michael was on welfare, he became familiar with the system of soup kitchens, drop-in centres and missions which he continued to use after his diagnosis. His situation

was followed by the CLSC. Six years ago, Michael married a Quebecker and his welfare was cut off. She has a well-paying job, which apparently is still insufficient to support Michael and their daughter. Without going into the financial details of his marriage, Michael indicated that he has had to rely on a clinic to provide his medication since the new provincial drug insurance programme.

Michael has also spent some time in halfway houses and group homes. Although there is nothing particularly spectacular about this, Michael retells a disturbing story of one of his times in a group home. In this incident, Michael spoke of sexually assaulting another elderly female member of the group home. As shocking as his story was the nonchalant bravado with which it was related. It struck me again as Michael spoke of his arrests and placement not in jail but the psychiatric ward and his welfare benefits, that Michael was intimating what his diagnosis afforded him in terms of money, access to some services and mitigated punishment for his crimes. For Michael, his mental illness was one way of shirking responsibility while soliciting sympathy.

Near the end of the research, Michael was separated from his wife and sharing custody of his daughter. Centres' staffs were very worried when they hadn't heard from him for days. Rumours were abundant often involving a drunken binge. When he did show up, more I think for the company than the food, he brought his daughter. One of the last times I interviewed him, after his separation, he seemed to be struggling but determined to succeed. He spoke of sometimes just not being able to get up to soothe his daughter and stop her crying. Despite finding himself in the role of a single father and in a rut, he remained in good spirits and seemed to be committed to staying on his medications. Although his small bachelor apartment may have seemed dirty and unsuitable for a child, having an apartment is a success for him. He was able to be on his own with his own things and care for his daughter to the best of his abilities.

## Shelly

Shelly was employed at the centre where I met Michael, in the same extra programme that had once employed him. She was in fact the first person I met when I entered and although I was new to the project then, she still seems to me to have no outward signs of schizophrenia, at least for long periods of time. She was a large woman and at 35 years of age, full of energy. She attacked her job with vigour and several times told me how much she loved cleaning. Although she was friendly and personable, she didn't seem to socialise with everyone and I had the impression that Shelly really wanted to associate herself more with the staff at the centre than the users.

Shelly emigrated from the Caribbean when she was 17, following her brother and sister. She has been back twice but doesn't consider a permanent move because most of her family lives in North America now. She feels that living conditions back home are worse than they are for her here and she is too old to go back to school there and find her job of choice. "The depression, the financial problems, economy and it's going to be hard and the schooling." She also found it hard to see the changes in lives of her friends in the Caribbean: some of them having died. Shelly associates being 17 with good times in her life although generally she said that between the ages of 15 to 25 her life was going down hill.

At least part of the move to Canada involved her leaving a relationship that she was too young to be in. Although it seems that this was her brother's assessment and that her family worried she would become pregnant out of wedlock, Shelly has adopted this assessment herself. Her mother had died when she was ten and her father remarried.

Shelly wanted to go to cooking school here but had to support herself working under the table as a housekeeper and baby-sitter for five years before obtaining her residency status. After her residency came through, Shelly went to school and began to work two jobs. This was when she got her "nervous illness." Shelly gave up everything because she just couldn't concentrate on anything.

From Shelly's perspective, she was hospitalised because of withdrawal:

I couldn't sleep at night and used to sit all alone in a lonely place thinking and my family thought that I am getting sick because people don't sit by themselves. But I don't want to talk; I don't want to do nothing.

Shelly generally reflects favourably on her time in the hospital almost as if it were a spa. She spoke of personal contacts, baths and being told to relax. But within this story is another one of resisting eating and refusing "commands" such as to take her medication. She spoke of being cuffed to the bed and having her medication increased. Shelly says she was hospitalised for only three weeks and has been back twice since then. After her first hospitalisation, Shelly lived with her aunt who took care of her and showed her how to live autonomously again.

To Shelly schizophrenia is "some kind of mental illness that makes you do strange things like hearing voices or seeing things and makes you think that this is the last day of the world." Having been hospitalised though, Shelly now feels great. She has an active social life involving going to the bar once a week and she wants to take computer classes. "I find there is nothing to reject me anywhere or in any field or position that I want to become."

Shelly has struggled with her weight and recognises this as part of her battle with low motivation. It is also a part of the drop-in centre lifestyle that fosters sedentary activities and offers fattening snacks. Shelly herself seemed almost addicted to crackers and cheese spread. Other information also suggests that her weight gain is side effect of her medication. In any case, she is proud to have lost 85 pounds. This boosted her spirits. Shelly also spoke often of having a boyfriend but once recounted a story of being hit on by some man at a bar. "I haven't had a man in so long. I don't want one and don't need one anyway."

Shelly's independence and hopefulness is a direct result of a job at one of the drop-in centres and more generally, contact with a variety of community centres. At a women's shelter, Shelly is able to participate in art classes. Shelly talked about field trips and how the

job has allowed her to socialise with people like herself. She adores the staff and the extra money does a lot for her. This is in contrast to her last job before her latest relapse. As her story goes, she was successful as a packer but eventually encountered someone she worked with who was jealous of her success and prejudiced by her schizophrenia. "He was jealous of me making so much money even though I am schizophrenic." Through a series of events, and in the absence of her supervisor, she was fired. Eventually, someone in personnel said she could get her job back if as they told her, "you get a letter from your doctor, but don't say on this letter that you are sick, ill, because they wouldn't employ you because you have a mental illness." The stress of this situation eventually led to rehospitalisation. Upon her release, Shelly found herself eligible for unemployment insurance as well as a sick benefit.

In keeping with this episode, all of Shelly's relapses are centred on times of stress. As her brother tells her story, Shelly's problems were immediate after her emigration. Still depressed about the death of her mother, and overwhelmed by the success of others in Canada, she became increasingly obsessed with accumulating wealth. She overworks (two jobs during school) to this end, and like most people, never feels as though she's getting any further ahead. On the other hand having a job enforces her feeling of agency and productivity. Working is the fulfilment of a childhood dream and the job at the centre is what makes her feel like she is, "back again at the age of 17." Unfortunately, working as well as school pitted Shelly competitively with other family members who have degrees and careers, "not just jobs." I asked her what a relapse is.

When you have a relapse, that means that you are thinking about something really really stressful to make you be sick or you have something, a stressful thing like financial problems, no job, no friends.

Shelly seems to indicate that stress precipitates relapse. Although Shelly was relatively successful in managing her schizophrenia, clearly her reliance on drop-ins, low income and the label of 'hard to house' were part of a difficult, stressful situation and her schizophrenic lifestyle. In many ways then, this lifestyle would seem to predispose her to a



cycle of relapse. Quoting Zubin, Barham elaborates Shelly's understanding of her schizophrenia in terms of a vulnerability theory:

... the concept of schizophrenia does not imply a chronic disorder so much as a permanent vulnerability to develop the disorder. [...] Vulnerability theory takes the position that negative symptoms are neither an inevitable consequence of schizophrenic disorders [...] nor an intrinsic feature of such disorders. It argues instead that negative symptoms are 'essentially an artefact or a social consequence of having been identified, labelled, and treated as schizophrenic by medical specialists, relatives, close friends, and other members of the patient's social network.' Factors such as social isolation, labelling and loss of social skills may result in a deterioration of the patient's coping ability and generate what has been termed a 'social breakdown symptom' which may frequently be mistaken for permanent psychopathology. In a large proportion of cases [...], the negative symptoms of schizophrenia may be just a side effect of the 'noxious-niche which post-episode schizophrenics occupy in life' (Barham, 1997: 94).

Shelly does say she is ill: "I am schizophrenic." and elsewhere, "I am crazy."

However, she also believes herself in control of her illness. She says she is fine and never thinks about going back to the hospital. She also initially said she cut back her medication but then clarified herself. "Sometimes I take it, sometimes I don't, but I don't feel like ... I don't think I should be taking any medication at all." In another interview Shelly clarified further that it took her a long time to accept schizophrenia as part of her illness but she still doesn't believe that all the medication is to treat schizophrenia. She more or less selects medications according to her needs. She blames the medication for making her feel sleepy all the time and thinks it is a crutch she doesn't need. Shelly also said the medication prevents her from being happy and losing weight. She wondered aloud what any prospective husband would think of her. Shelly goes to church to pray to overcome her illness and get off the medication.

At the end of this research, Shelly's brother had moved in with her for a while but was later jailed for assaulting his ex-wife. This of course was another stressful situation for Shelly and the drop-in centre staff worried about her. In addition, the limited term for her work programme was running out. I saw Shelly again several months later, after her brother's release. She didn't have a job but hoped to soon be eligible to work at the centre again. She was happy and spoke about returning to school in the winter.

## Carlo

Carlo is also from the Caribbean. I did not meet him at a drop centre but rather at a long-term residency. Through the director, he approached us to do an interview. When I first encountered him, he had difficulty moving particularly his legs and was aggressive towards the female interviewer I was with. Nonetheless, over the course of the project, he seemed to warm up to us and he was one of very few who I would often see out in coffee shops. Sometimes, he would approach me or I would approach him to chat. More than any other informant, Carlo for me illustrated the peaks and valleys inherent in schizophrenia. His moods ranged from aggressive to charming and charismatic. Some days he was out just enjoying the day while on others, he spent hours in the recreation room scribbling messages, deciphering codes and creating anagrams out of his name. Again, although it was never my intention to discern or extricate truth from what the informants understood as truth, Carlo stands out because his narrative, beyond the confusion, remains so believable despite its unbelievable parts. Carlo more than any anyone else challenged my scepticism toward the coherency of psychosis. By way of an illustration, he often spoke of his father who was a renowned psychologist and who worked as a detective for the United Nations. He also spoke of his world-renowned mother who was a psychologist based in England. Both were true. Part of his story is as follows.

Carlo's age was hard to discern only because he gave two ages. One is gleaned from him emigrating at the age of ten in 1970 making him 36 when we met. But, during our first interview, he did outright say that he was 24. Details of his age are largely unimportant but this mix-up undermines his time line making his life history difficult to map.

Carlo immigrated to Canada after being approached by the Canadian government to study. He lived with and looked after his ageing, blind father before being placed in a group home then into independent living under the supervision of Social Services. He says he managed to save the money he was getting but went to the hospital where they paid him to test medication. He resisted this but: "the more I tried to back out of it the deeper they put

me into it.” Although he tried to leave the country, medications were eventually tested on him. After they were tested on him he was diagnosed as schizophrenic and manic-depressive. Not in the hospital, he refused to take his medication for three years, when an incident with his landlady involved the police and the re-emergence of his diagnosis.

My landlady got violent with me over - over my money, and I grabbed her and shook her up. They said that because I got aggressive with the landlady, I'm a schizophrenic [...] Every time I'd get aggressive with somebody, they phone the police and tell the police to bring me to the hospital.

Interestingly, being labelled as schizophrenic and violent reveals the lie being perpetrated on him.

But what I know, schizophrenic people don't hurt nobody. They supposed to be scared of people. So the crime I committed against my landlady, I've no reason: there was no reason for me to go to the hospital, or to take medication for schizophrenia, or manic-depressive or anxiety.

In any case, Carlo was rehospitallised, and moved around within the hospital system. More medications were tested on him. Eventually, “because they lie, they have to have a court behind their back,” a court order permitted the doctor to give Carlo medications forcefully. Five times he almost died.

Carlo's native home government also got involved and questioned the Canadian government about how Carlo could become schizophrenic.

In 1985, his father was tricked into signing a paper to put Carlo under the trusteeship of the public curator. His blind father signed the paper after having been told that it was in fact a document to release Carlo from the custody of the hospital to his (the father's) custody.

Carlo is no longer in charge of his own money and not only does he feel robbed, but also powerless. “I went for candy or a soft drink and I cannot have it [...] because they have all the money.” In addition, his attempts to regain control over money, as was the case with his landlady, inevitably lead to conflict, police intervention and rehospitallisation.

Carlo sees himself as unfairly being an object of the courts and its judicial powers. He feels particularly cheated that court orders forcing medical treatment were handed down

in his absence. Although he has friends to assure him that he is not sick he feels that the system is abusing him because he does not have any family in Montreal.

“Whatever they talk, the court the court believes them. But the court never sees me! I’m never present in the courtroom for the judge to say. ‘is this true?’ Do you have any family present with you to prove that this is true?’ I have no family whatsoever<sup>15</sup>, so they do whatever they want and even try to kill me.”

Carlo’s distrust of hospitals increased after his father and two cousins died while in a hospital<sup>16</sup>. The deaths and his own victimisation by the hospital make him question the efficacy of the hospital as a place to get better. His issues with the public curator combine with stories of other abuses to attack administrations, power, authority and how they play out (and with) the situation of the schizophrenic.

I remember the staff, one of the staff at the --(names a hospital)--. She, you know what she did? She used to fool around with me and sex, sexually. Now whatever, look, you’re staff, I’m a patient, I can’t do what you think I can do with you. So you can leave me alone, if you don’t leave me alone I’m gonna press charges. She says, ‘you think you’re gonna press charges, I’m gonna tell the doctor a bunch of lies about you and your ass is going to go to the --(names a different institution, largely for the criminally insane) for a long time.’

Carlo was sent to the “institution” for three and a half months where he underwent an invasive strip search.

Eventually Carlo was released first to a group home before moving on to where we met. He said that here although things were good, “you get three square meal a day and you can do your laundry,” his medication doses were too high making him constantly sleepy and turning his legs numb:

But these guys just packs it on, they don’t care. They don’t care about no one but themselves. As long as they get the Medicare card, they push it or they get paid, that’s what they do. They just stick it to you.

For his part, Carlo’s biggest dream is to return to his native country where he can relax and “recuperate.” Carlo suffers from many side effects and looks forward to getting

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<sup>15</sup> Carlo did speak of family back in his native country.

<sup>16</sup> Carlo’s father died several years earlier. Carlo spoke of a mix up with a blood transfusion in which his father was given contaminated blood.

off the medication because as he said, "it messes up my penis, messes up my lungs, messes up my stomach and messes up my head." He would like to finish his studies and become a psychologist like his father. Already he knows "quite a bit about reverse-psychology."

Once I bumped into Carlo as he was doing laundry at the residence. He had been recruited to do some factory work over the holiday season and had not been taking his medication. He looked healthy and said he felt great. Speaking with him for a few minutes as he sorted and loaded his laundry into the machines, I was struck how agile, focused and friendly he was. Several months before the research ended, I was informed by one of the workers at the residence that Carlo had been arrested for beating an 80 year old woman nearly to death.

Looking back on these life history vignettes none is striking as a schizophrenic 'ideal type'. However, each illuminates well at least one of the five phases.

It is, as expected, impossible to validate prenatal or early postnatal brain development as a source of schizophrenia although Shelly and her brother may superficially suggest a genetic predisposition. Shelly's social withdrawal and reduced drive and motivation fit well the expectations of the prodromal phase while Michael's voices are in line with the psychotic phase.

Staff ensured that only those who were not experiencing florid symptoms were interviewed. Because of this, being in the residual phase was a requirement for the interviewees.

The relapse prodromal as manifest in the informants seems less a result of biological disequilibrium than of specific situations. It may be easy to pin point stress as such a situation but equally culpable are the good times during which the informants felt "great" or in control and no longer reliant upon, or in need of their medication. Feeling great, makes relapse seem unlikely to the schizophrenic. For caregivers however, going off medication makes relapse seem predictable.

For the informants as well as those around them, the actual diagnosis of schizophrenia serves as an explanation for their situation. For us it explains a variety of odd behaviour exhibited by the person ranting aloud on the street or the man who pushed another before the subway in Toronto last year. For Michael, schizophrenia explained the voices: for Shelly the social withdrawal and for Carlo it was part of a conspiracy theory. "I'm being brought to take some medication so they can get hold of my money."

By looking at these informants as being in some phase of a cycle, it also occurs to me that this cycle is part of a process in which the participant is forced to make the best of a potentially deteriorating situation. What is surprising then is the informants' own perspective, uncluttered by the potential pitfall of relapse. Whereas a diagnosis of schizophrenia would seem to trap schizophrenics in a cycle marked by the five phases, clearly for the schizophrenics, such a diagnosis is not only an explanation but also, despite its setbacks, a route to triumphing over a bad situation.

## Chapter 8 - Non-Conformity

The next chapter looks at what deinstitutionalisation may mean in terms of non-compliance and the agency which schizophrenics are able to exert now that they are no longer restricted by the rules of an institution and free from constant surveillance. In anticipation of that, this chapter presents one life history which illustrates that although clinical non-compliance in an institution may have a particular form, on the outside society's rules are also demanding although less clear. One informant, Chuck tells his story in this chapter. He is able to tell his story of schizophrenia as one of resistance where non-compliance is non-conformity.

Medically, non-compliance is the failure or refusal to follow or otherwise abide by a medically prescribed regime. Non-conformity has broader implications and means a failure or refusal to conform, as to established customs, attitudes, or ideas. Once it can be established what a failure may be, questions then arise as to what are the appropriate sanctions.

### **Chuck**

Chuck's story expands what schizophrenia is by exploring the possibility that the disease is a moral judgement. As Chuck configures the disease non-compliance is really a resistance to social norms.

I first met Chuck in 1997, while he was working at one of the drop in centres doing general duties, but mostly cleaning before closing. It was unclear if he was being paid or was volunteering since several others also carried out similar duties although not as regularly as Chuck. His position in the centre was distinguishable by the fact that staff seemed to a certain, albeit limited degree, to rely on him.

I enquired about his status and whether I could approach him for an interview; staff confirmed him as schizophrenic. But because of the new health insurance programme was now requiring that people pay a portion of their prescription bills, Chuck was not taking his

medications because he couldn't afford them. I was told it would be better to approach him in a few weeks.

Eventually, with a second interviewer, I did conduct an interview in which Chuck spoke almost non-stop for about two hours. He had so much to say that at the end of the tape he asked if we had another. Despite all he said, he was less interested in revealing himself than providing a social commentary. He was tense and evasive about his family. This may be a result of limited contact with them in addition to being institutionalised from childhood through adolescence and because of the drugs, having few clear, cohesive memories.

I later learned that Chuck had done two interviews in 1995 with two other interviewers<sup>17</sup> while the research project was guided by a slightly different mandate<sup>18</sup>. His story as presented here is a collage of all these interviews but begins with his first at age 38. The following is a quote from one of the earlier interviewers, assessing Chuck during his first interview.

Chuck seems to be a very eager storyteller, yet it is obvious that he is very eager to be listened to. His story is not easily revealed, leaving one to wonder if he actually has a story to tell. He seems to want to control our reactions with his pauses, mumbling, periodic outburst of laugh[ter] (when least expected) and wide grin. At one point I had a sense of witnessing an act, whereby he would burst out in exaggerated loud laughter, as if he was imitating madness or craziness. He is a smoker and uses the cigarette as a prop from which he takes long draws, to pace his delivery. He would sit back, with one leg crossed over his knee and pose as if in deep reflection, one hand cupped under his chin.

These observations seemed accurate and expose the type of control that Chuck exerts. As his stance and narrative tell us, he is in control and won't hesitate to shut things down if they don't go his way. More than any of the other informants, Chuck believes himself to be fully independent from society.

Problems with drugs lead him to be institutionalised where he was alternatively

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<sup>17</sup> For these interviews I thank Francine Robillard and Pascale Annoual.

<sup>18</sup> I believe this mandate looked more generally at mental illness and deinstitutionalisation.



diagnosed as retarded and hyperactive. From the age of nine to fourteen, he stayed institutionalised. He was too young before his institutionalisation to have many memories of his childhood and because of his drug regime during his institutionalisation, has few memories of that time either. The following two excerpts illustrate how foggy his memories are.

You know, everything was a blur. I couldn't make out faces. I don't know if they were black or they were white or, all I know is they were light skinned and my eyes were blurred and I couldn't, my eyes couldn't focus to get a clear picture of each face, and that is about the last I remember. That was the first and last time I had a visitor.

I don't remember the particular, but I remember there was times when I was sitting in some sort of classroom, learning something to do with English or something with academics and the brain was out of it. But it was eager to learn on one side and the other, it was just pulling because it was too drugged to, maybe, perhaps comprehend even though the eagerness and willingness was there. I tried, under extreme circumstances, to comprehend but the drugs were too powerful to even want my other side of the brain to accept to at least try. So, that was the situation.

Chuck told only two stories of rebelliousness. He remembers running away from the institution with a few friends. He doesn't remember where they went, slept or ate but does remember returning and being refused dinner. Another time, at Christmas, he "freaked."

One day, it was Christmas time and I freaked, like One Flew Over the Cuckoo's Nest. I started running in the hall 'ah! ah! ah!' all over and through the tunnel upstairs and I smashed the door, the Christmas tree.

Chuck moved at the age of fourteen to some sort halfway house and attended school. He has general, fond memories of being there, mainly typical stories of playing with other kids. Being out of the institution begins a time of growing awareness.

When they gave me my freedom, what I, after a couple years of freedom, I started thinking, I started seeing thing in front of me and being able to think, to evaluate and make some, you know judgement...

He did have difficulties in school and moved from one to another. Whether or not he was able to finish school is unclear although he did mention attending college in Toronto for a while. In any case, at 18, Chuck started drinking.

I was about 18, going on 19 and I remember I had my first beer as an

independent person [...] I didn't know I had so much anger. I didn't know I had so much hurt. I didn't know I had so many unsolved questions, and my first beer was, like, all of a sudden it came out that I didn't, that I was not aware of, and couldn't believe in society.

Chuck spoke about drinking everyday and being a junkie for five years. He also spoke about travelling, visiting and living in a few different places such as New York, Vancouver and Toronto. He claims to have been arrested only six times. Chuck has apparently been battling a drug problem for most of his life. No doubt this and his mental health have been behind many of his incarcerations. Some of his arrests involve other incidents such as either being beat up by the guards or the other inmates and one in which a prison guard told Chuck to go back to the country where he came from. Retelling these stories was part of Chuck's social commentary. Although Chuck's commentary was often peppered with an interpretation of racism, his prison stories were more concerned with different notions of freedom, particularly the different limits on freedom imposed by jail as opposed to those of the hospital/institution. At one point during an interview Chuck drew a sharp distinction between being arrested and being helped.

I mean what the fuck gave anybody, whoever in the fucking society gave the right to punish people 'cause they got a drug problem, because they have to steal for their drugs. Whoever gave them the right to put these fucking people in jail. I mean when I came out of hospital I had just, this just came to me. I think about it and it's disgusting, who gives the right to lock a fucking junkie and who, you know what I mean? If they've got a drug problem, give them the fucking drugs, send them to somebody like a professional [...] where they can have a support system and try to see, help them to find themselves or what they want to do.

Another time however, Chuck contrasted being jailed with being in a psychiatric institutionalisation.

You see, when you live in a mental hospital, it's not like jail. You're fine in jail. When you live in a mental hospital you don't come out fine.

In jail Chuck's problems were physical. Whereas in jail he spoke of racism and being beaten up, in the hospital threats were to his individuality. In the hospital, neither able to understand what the medications were for nor believing in his diagnosis, he was forced to take medication against his will. Chuck believes that he was institutionalised because

society was not ready to deal with him and people like him. Institutionalisation was a process of conditioning, meant to force him to behave within normal social parameters.

... those mental patients, you know, they're like everybody else. Somebody's good at something and somebody's not. Somebody can pick up things, things if they went to school or read books on it and can pick it up like that (snaps his fingers) and there are people that are slow at some things and fast at some things and don't have a mental problem classified in society, you know, and so on and so on. So they're no different from anyone else but like everyone else that's what it's about. We cannot train this individual like they've done with 99% of society. So we're talking about 26 million people, 28 million in Canada and we're talking about 28 million people who've been trained to walk in Frankenstein, Dr. Frankenstein's footsteps, and 100,000 refuse [...]

Chuck often used Frankenstein as a metaphor for society and would later explain that even though he was a product (Frankenstein) of society (Dr. Frankenstein) he should not be obligated to follow all that society dictated (what Dr. Frankenstein ordered). He refuses to walk in Dr. Frankenstein's footsteps.

Later he says, "they put me in the mental hospital and many other children in the mental hospital just to keep our mouth shut so we don't unravel people's minds..." In another interview he added:

...but unfortunately I'm different and that's the way they trained you to look at me. I was different. Intelligent but different. That's a problem (laughs), but we're not ready to deal with that yet, because that would be a big switch (chuckles).

Chuck, as was the case when we met, is sometimes off his medication. Like other schizophrenics, there are a variety of reasons for this. When I had first encountered him, changes to Quebec's health insurance programme were still relatively new and Chuck had been having difficulties adjusting his meagre resources to pay for his drugs. Eventually the drop-in centre loaned him some money. However, Chuck has always been suspicious of medications and even while institutionalised had often had to be forced to take them.

I didn't want to take the medication 'cause I'm always high and I was asking [...] 'why are you giving me these pills?' and so I said, 'I'm not taking them' so two or three grabbed me, and I tell you, I was very strong. It used to take them half an hour to get me down.

He also told the story of how while living with his family his brother took him off

the medications.

Well, when I lived at home my brother took me off them [the drugs] because he found that every time I ate supper, after a couple of hours all I would do was sleep.

Sometime while living with his family, Chuck was arrested for some crime and had a social worker assigned to him. The social worker did not put Chuck back on the medication.

Chuck also spoke once of breaking up with a girlfriend and being too stressed out to work.

I was really screwed up at the time. I was in a serious relationship and it was just going backwards. And I was very, very, very in love, you know, and I still love her today. (laughs) But, I have to get over reality right?

Although social integration was and remains a goal of psychiatric treatment, marginality and isolation are central states of being for the stigmatised schizophrenic. Often unfit for long term, permanent or full-time employment, and termed "hard to house," schizophrenics remain on the margins of society. Chuck is also one of many people who are termed, "hard to house." This term is elusive in that I am uncertain not only who assigns it but also how it seems to stick. People labelled as hard to house obviously have difficulty finding and keeping homes. In general, part of the schizophrenic lifestyle is repeated periods of rupture where relapses and reinstitutionalisation often mean that bills and rent go unpaid such that upon release from an institution, the schizophrenic finds himself evicted and possibly his possessions seized. Without an address, it is impossible to collect welfare and other benefits. One landlord I know who has had experiences renting to people with mental illness indicated that unpaid rent was a small problem compared to other problems the most frequent of which involved the renter disturbing other tenants. For Chuck however, having a residence is another social conformity that he would rather do without.

I would live on the streets today if it wasn't for people's prejudices, their jealousy towards people living out on the streets. It's a good life and you don't have to suck ass [...] You have responsibility to yourself.

Chuck detailed two difficulties he had which illuminated problems getting and maintaining an apartment. Like most schizophrenics, Chuck is highly mobile and often spends several days if not weeks away from home. With a limited budget often unplanned bills are hard to meet and usually unexpected.

I've been out of my apartment for four months because Hydro Quebec's trying to con me out of \$500 [...] When I was living in Ottawa for six months I was only home for about two days. [In February] they mailed me a bill for \$159 and \$90 and I called them up and asked 'what's the \$150 for?' and he says, 'well the \$81 is for your hot water tank and the \$150 is 'cause you lived somewhere else and forgot to pay your bill.' [...] So the next month I get home, I get a bill for \$200.

This vignette exposes the vulnerability of schizophrenics. Given the extreme weather during the winter, it is not inconceivable that his bills would be \$200 per month even to heat minimally so that the pipes wouldn't freeze. In this case Chuck's budget and inability to plan not only disadvantage him but his marginality and *limited* funds place him at constant risk for homelessness as well as preventing him from later<sup>19</sup> being reconnected to Hydro Quebec since he will likely not be able to pay his arrears.

The example that Chuck's life history affords is that while the institutional setting with its constant monitoring and insistence on adhering to the regime made non-compliance negligible it also meant that non-compliance was a failure of the institution to effectively carry out its mandate and press its authority. Deinstitutionalisation would seem to mean the withdrawal of that authority and type of monitoring. Chuck's story questions this and reveals that the exigencies of living on the outside also place one under scrutiny and authority albeit ones more subtle and diffuse. If deinstitutionalisation seems to be partly predicated on voluntary compliance it is buttressed by the rigours of conformity.

Once I witnessed an attempt by one social worker to convince a diagnosed schizophrenic, Mathew, to have his file at the Douglas Hospital transferred so that the social worker could assess him more thoroughly. Mathew refused and was threatened with institutionalisation since it did seem that his situation was deteriorating. Later though the

social worker informed me that even without the consent he expected to get the information he needed from Mathew's psychiatrist as part of professional courtesy. This exemplifies one of the odd examples of how a concealed power was used to thwart the schizophrenic while testing to see if something was wrong. Mathew's defiance and refusals were indicators that something was wrong. He may have been trying to hide the severity of his diagnosis or he may have been suffering paranoid delusions. In either case, his refusal was not interpreted as a normal exertion of privacy. Since consent was ultimately not needed, this confrontation could have been avoided and was only the expression of authority. This encounter also exemplifies the diffusion of authority to the point where a social worker, rather than a psychiatrist, invoked institutionalisation (as threat).

Chuck offers a different understanding of what non-compliance is beyond that of adhering to a medical regime. When Chuck suggests that the only thing keeping him from choosing to live on the streets is other peoples' reactions he questions what the consequences are for non-compliance. In that example consequences range from all sorts of social sanction, such as no social assistance (without a permanent address) and likewise, loss of access to other community social services. He is able to collapse his compliance into maintaining a social system with which he colludes by reason of its inescapability.

For Chuck, compliance and conformity are the same thing. Both are meant to restrict alternative ways of being and maintain the status quo. For many schizophrenics however, cyclical institutionalisation, marginalisation, alienation poverty and other problems are the status quo. In the video "I'm Still Here," Fred Frese similarly makes the point that schizophrenics may offer some insights into social problems.

I think we've got something to offer. You normals, have you noticed how you've screwed this world up? I mean have you seen the crime rate? The divorce rate? Your families falling apart? You guys need us bad. I mean you had us in these state hospitals [...] we're all out now. We're ready to help you out.

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<sup>19</sup> It is illegal for Hydro Quebec to disconnect customers during the winter months.

For Chuck, his diagnosis was meant to bring him in line with social norms and cultural expectations. Designation as a schizophrenic marks him as expressing "norm-violating behaviour" (Sarbin and Mancuso, 1980: 10). For him, how these norms and expectations are encased by laws, enforced by sanction and buttressed by a range of professionals (e.g. psychiatrists), workers (e.g. social workers) and institutions (e.g. jails, hospitals) is the manifestation of a cultural system. Quebec's *virage ambulatoire* is but one example of this system's relevance to the state of illness: its aetiology and the establishment of conditions for successful therapy. Just as Chuck seems to understand how his behaviours eventually came to be reconfigured as symptoms, he also implicates treatment as illness. This was particularly true for his analysis of the inefficacy of locking up alcoholics. Chuck's desire to be homeless, and disdain for a society that jails alcoholics, more than expressive of a want to withdraw participation, is an attempt to offer a socio-cultural alternative. The feasibility of the alternative is blocked since Chuck's diagnosis with schizophrenia explains even the offering of an alternative as part of his psychosis. Indeed, as far as Chuck may understand his experiences of schizophrenia as an alternative to Taylor's rational self, he exemplifies how the only alternative the rational self has left open (has vacated) is that of madness and psychosis.

## Chapter 9 - Agency & Non-compliance

Non-compliance is the refusal of a schizophrenic to follow his drug treatment. As a means of subverting treatment, it allows the schizophrenic to confront his treatment and diagnosis. Non-compliance is the assertion of agency and the denial of the passive role in which the authority of psychiatry has cast the schizophrenic. This chapter examines what non-compliance means to schizophrenics and their carers, what opportunities it offers and obstacles it presents.

Compliance is "the extent to which a person's behaviour coincides with medical or health advice" (Hayes, 1979: 2). Conceptually it may seem no more than part of a paternalistic patient–doctor relationship, but non-compliance for a variety of diseases is "one of the most vexing challenges in psychopharmacology" (Fenton *et al.*, 1997: 637).

Non-compliance, to those caring for schizophrenics, is the failure or refusal of a schizophrenic to comply with a prescribed medical regime. Non-compliance is strongly implicated in all research on rates of relapse, re-admission to institutions and criminality. In its broader definition it is the failure or refusal to comply with the terms of an agreement. Sanction for non-compliance is often swift and severe. For the users of the centres it usually means being banned either indefinitely ("for life"), for the day or until such time that the schizophrenic complies. Non-compliance is for social workers and psychiatrists, a warning, precursor to relapse and a sign that stronger intervention is necessary. This usually takes the form of forced hospitalisation. Non-compliance is a scale representing degrees of compliance and not necessarily an absolute disregard of the medical regime. Non-compliance may include errors of omission, mistakes in dosage and timing and the inclusion of medications not prescribed (*ibid.*).

One director of a drop-in centre, Annie, spoke about non-compliance during an interview. She was sympathetic to what may cause non-compliance and in some ways



questions why compliance is such an essential part of treatment when there are no "miracle drugs."

There are people who can function with their illness without being medicated. And they function marginally, but as long as they're not a threat to themselves or to others I don't see a problem with that. I don't see the reason we should force someone like that to take medication if they don't want to. But there are people, who cannot, who keep getting into trouble. Over and over again because they refuse to take medication because first of all the medication is not a miracle drug. It doesn't alleviate all the symptoms and it does very little for the negative symptoms of the illness, which are the symptoms that cause people to isolate [...] which is very common in schizophrenia. The medication does very little for that. It does more for the positive symptoms which are the hallucinations and the delirious thoughts. [...] And plus it has a lot of side effects. So I think we can understand why people don't want to take the medication. Side effects such a shaking, dry mouths, sometimes they feel like their muscles are tense. That's all due to the side effects of the medication. [...]

I think with age people will understand that they're better off taking the medication than not taking it. When they don't take it they get into trouble. They're brought in jail. They're brought to the hospital against they're will. They're medicated against their will. And we try to make them realise that they have a lot more control over their situation if they accept the follow up. That way they can deal with the doctors. They can say what exactly the medication does or doesn't do for them.

Annie raises the importance of the follow up and the role of doctors. She also knows though that follow ups are difficult for reasons that are not always the schizophrenic's fault. Sometimes, doctors are unable to empathise with the schizophrenic's side effects and hence avert non-compliance. Part of what all these complicating factors hint at is that compliance is essential to deinstitutionalisation but not necessarily successful treatment.

<u>Disease</u>	<u>Non-compliance rate<sup>20</sup></u>
Schizophrenia	40-55
Arthritis	55-71
Seizure disorders	54-82
Bipolar affective disorder	20-57
Diabetes	19-80

(Chart compiled from data in Fenton *et al.* 1997: 637-638)

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<sup>20</sup> Fenton *et al.* point out that the studies are inconsistent by using a variety of definitions and detection methods. (Diabetes for example has a broad range since non-compliance could mean anything from eating sugar and salt to failing to maintain insulin injections.)

The positive, cognitive and disorganised symptoms of schizophrenia imply that non-compliance may be part of the disease process. Paranoia, grandiosity and disordered thinking are thought to establish a "catch-22" situation in which the schizophrenic, lacking insight, refuses medication and either develops more symptoms or increases the severity of others. Citing other studies, Fenton *et al.* compare non-compliance rates among different disorders (see preceding chart).

### Possible Causes of Non-compliance

Compliance may exact a heavy toll in the form of side effects. Choosing not to comply with a medical regime is one possible way to seize control over a situation and deny the authority of caregivers. Drawing on information in Fenton (Fenton *et al.* 1997: 641-644) and information on Dr. Peter Weiden's web site (Weiden, 1999) the following is a non-exhaustive list of possible causes of non-compliance.

1. Side effects such as akinesia (feeling like a zombie) and akathisia (an internal feeling of restlessness/jitteriness) are unpleasant and can either cause the patient to go off medication or prevent them from beginning the regime.
2. Negative symptoms often include low energy and motivation making it harder for compliance to be adhered to without help and supervision.
3. Complex regimes are often difficult for schizophrenics to follow.
4. Dosage, agent and route are statistically implicated. Injections (as opposed to oral medications) and low dosages are associated with higher compliance rates.
5. Practical barriers, particularly the inability to pay for medications increases non-compliance.
6. Alcohol or recreational drug use may inhibit the schizophrenic's ability to follow through with a regime or cause them to stop taking prescribed medication so as to avoid mixing drugs.
7. Family or therapist opposition to drugs may encourage a schizophrenic to not take medication.
8. Psychological meaning attached to the medication by schizophrenics influenced non-compliance rates. Authority, control, dependence and addiction are all associated with drugs.

Non-compliance, not taking medication, differs from non-response where the medication fails to work. In either case the result is likely relapse but the cause of the relapse may be difficult to ascertain. Whereas non-response is no-fault, non-compliance is the fault of the schizophrenic. (Whose disease indicates a lack of control, of competency, of culpability.) Fault as an exercise of agency is one of the few venues open for the schizophrenic to exert control.

Point five seemed to be the most common reason for being non-compliant. However, suggesting an inability to pay for medications implies a situation in which the schizophrenic is without funds. Realistically this was not the case since almost all the schizophrenics interviewed were on social assistance. Social assistance in itself is generally quite limited and requires an established budget within which choices need to be made. That many of the users of drop-in centres, had drug addiction problems to which a large portion of their assistance went, is undeniable. Glen was known to sign his social assistance cheques over to his janitor/drug dealer. Others, like Richard and Michael, had children and family and even if they managed reasonably well during the year still had to figure out how to financially cope with such things as Christmas gift obligations, supplies for back to school and presents for anniversary events. One informant who did not have custody of his children, chose to live on the street during the summer months in order to afford to buy his children things for school in September.

### **Expanding Non-compliance and Exerting Agency**

Because there is no cure for schizophrenia and medications therefore can only alleviate the symptoms of schizophrenia and suppress psychosis, non-compliance is in many ways a refusal to accept palliative care and is therefore larger than a breaching of the medical regime. It can be expanded to include breaking rules and social norms. To not resist even the potential for psychosis is to challenge Taylor's modern individual (Taylor: 1989). Obviously these social norms have a broad range and the most basic ones dealing with threatening behaviour are not in dispute. However, degrees of (for example) aggressivity, agitation, cleanliness and even being uncooperative are not necessarily dangerous. These are however also used as indicators of non-compliance and in cases such as these, the medical regime is used to enforce social norms not only through medicalisation but threats of sanction.

Non-compliance for the schizophrenics is one of their venues to exert agency. **Schizophrenics have limited choices and even to avail oneself of the charitable services of**

others requires a subservience that buttresses power structures and the validity of the medical regime. Schizophrenics have no room to dispute their diagnoses since to refuse the diagnosis is to be non-compliant. For many though the alternative is collusion with the medical regime and consequently complicity with their situation.

Pamela Wagner in her web site relates how side effects to many medications made her stop taking the drugs. Wagner's non-compliance was seen as a wilful rejection of sanity rather than expressive of an intolerant situation. She was not initially allowed to be involved in her treatment. Unable to be proactive, her non-compliance continued until she was placed on a medication that she could tolerate.

For years, I was maintained on Prolixin, though not all that successfully, since I still wound up in the hospital once or twice a year. I hated the stuff, refused to take it on my own, which was one reason I received long-acting injections. My 'non-compliance' was seen as wilful rejection of sanity rather than a reaction to the extreme discomfort of the side effects the drug produced (Wagner, 1999).

In Wagner's case, talking with her doctor and even the severity of side effects did not facilitate a change in her treatment. Wagner's non-compliance became a tool she was able to exercise in an effort to obtain better medication. Wagner continues with her story after having been switched to another medication which just seemed, "no worse" until she reached what she terms the "therapeutic dose."

... all hell broke loose, with seemingly every side effect in the book and then some. Profoundly sedated, I was awake maybe eight hours out of every twenty-four. Then the drooling started, and an inability to swallow my saliva that came on an hour or so after I took my nightly pills. Worst of all, though, was an agonizing sensation I called 'the electrocution feeling.' This last - later thought to be result of pre-seizure activity in my brain - was largely ignored, since it didn't seem to my doctor to fit in with clozapine's 'side effect profile.' It was, she decided, my old 'wilfulness': I simply didn't want to get better; if I did, I'd put up with the side effects, no matter how bad (*ibid.*).

During many observations, non-compliance was often feared not when the schizophrenic appeared to be off their medication but any time they posed a threat to staff, users or the social environment of the drop-in centre. This required the workers to see the schizophrenic only as medicated subjects rather than people with a range of emotions.

Expressing anger for instance was unacceptable even if situationally understandable or appropriate. At least once a week at one centre or another someone (not necessarily anyone with a mental illness) was barred from the centre. It was clear when asking about why the schizophrenics were barred that non-compliance with the rules of the centre was being collapsed with non-compliance of a medical regime. Invoking medical non-compliance when in fact the conflict was with centre rules legitimated sanction. For anyone other than perhaps the doctor, psychiatrist, and the pharmacist, it was impossible to be certain that people were going off their medication. Some people were confronted who said they hadn't quit their regimes while others confessed to having been off their medications for weeks. Often in the *milieux* of the centres with their lack of privacy, diverse characters, the noise and limited resources (one television), provocations were frequent. A few users were known to delight in tormenting other users, sometimes reducing them to tears. Other times there were confrontations that turned violent either because of the situation itself or as a sort of clarification of the pecking order. The centres' environments, like elsewhere, were always pregnant with potential conflict and confrontations. If it was impossible for staff to command the whole environment all the time, then reactions and outbursts were controlled through rules and regulations with which the user was expected to comply.

Behaviours however, just as they may be taken as symptoms of schizophrenia are also indicators of social and/or medical compliance. At this point, behaviours incompatible with the rules of the centre and those indicating clinical non-compliance are for many, indistinguishable.

Often in the research, users of residences would speak of the three meals provided for them only to refuse to eat one, two or all of them. As I came to understand this refusal, it was an attempt to dispute control by authorities and exert agency. One man, Henri, stands out as a good example because he seemed to always refuse to eat during mealtimes yet in his interviews eating outside of the residence was significant in his narrative. Eating outside of the residence always took place at his mother's home on the weekends and one of the

conditions for his mother allowing his visits was that he keep up his medications. Henri was tremendously attached to his mother and looked forward to his visits with her. Her restriction however cut off one of few venues open to him to dispute his diagnosis and treatment. Nonetheless, when he refused to eat meals that he admittedly found appealing, he maintained his body as a sort of disputed territory. One of my colleagues even commented that Henri, being slim, didn't look like the other residents on whom the affects of regular feedings and little exercise were very apparent.

Henri indicates that medical non-compliance as well as more general forms of non-compliance are often about the body. Schizophrenics as with other marginalised groups have few tools to deploy to exert agency and one of them is the body. What is ingested, the use of caffeine and nicotine, form and physical comportment were tools with which circumstances, diagnoses and treatments were confronted and disputed. Schizophrenics like Henri used the body symbolically to convey a range of other social, political and psychological states of being and in doing so, limited the intrusion of their psychiatric, biomedical diagnosis. Non-compliance is an important method of distancing oneself not only from the label of schizophrenia but from other schizophrenics and the network of institutions and people that care for them.

### **Stigma Aversion and Non-compliance**

Returning to Shelly and Carlo allows other insight into different aspects of compliance and non-compliance and how these are implicated in stigmatisation.

Shelly also spoke about gaining weight while on the medication and as a result of this association used to go off the medication to lose weight. Shelly was forthright about not taking her medication although once I asked her if she knew what non-compliance was and she was unable to answer. She is proactive when managing her medications and spoke about having them switched around to alleviate side effects. She once told me about being on medication that she felt disagreed with her and going back to have it changed. With so many medications out there for her to choose from, she described her choices as, "the

difference between Coke and Pepsi.” Sometimes one just prefers one over the other.

Shelly is not only active in her treatment but unlike most others maintains constant contact with her social worker and psychiatrist. Shelly also identifies herself as *being schizophrenic* and *crazy* rather than *having schizophrenia*. By doing this, Shelly is able to expand the meaning of schizophrenia and offer it as an explanation for other behaviours as well as a reason for how she was.

... wherein a noun denominating a disease could be rendered into an adjective predicating a person. This transformation from a patient being diagnosed or suffering from *schizophrenia* into a patient being *schizophrenic*. Hence qualities came to pervade the total identity of the patient ... Patients who in the first instance are described as experiencing the onset of an episode of schizophrenia become redefined through this subtle but powerful transformation into patients who have had the seeds of schizophrenia in their biological origins, who come to express their schizophrenic identity in all aspects of their person, and who remain schizophrenic even after recovering from that initial episode (Barrett in Barham, 1997: 90).

Estroff, similarly makes a sharp distinction between “I am” illnesses (e.g. “I am diabetic”, “I am alcoholic”, “I am epileptic”) and “I have” illnesses (e.g. “I have cancer”, “I have arthritis”, “I have cystic fibrosis”). For her, “I am” illnesses mark the fusion of self with sickness and identity with diagnosis creating the consequence of chronicity. Illness becomes inextricable from self and hence cannot be disjoined from the person. Chronicity results through the continuity of a self indistinguishable from the illness. She continues to illuminate the special role that chronicity and disability have to time. Referring to Klienman and Kaufman, Estroff states the following:

First, when pain or dysfunction persists in the face of efforts to heal and recover, customary explanations may be replaced by other categories of response and understanding. Lack of recovery requires a shift in healing tactics and/or explanations for the affliction. Second (and consequently), suspicions may increase regarding the role of will or individual unwillingness to become well, especially in the West where biomedicine does not accept defeat gracefully. Finally, profound alterations of self and identity are more likely because the prolonged presence of symptoms and impairments erodes denial of dysfunction (Estroff, 1993: 257-258).

Returning for a moment to Morris’ distinction between illness and disease or the subjective experiences of sickness (an illness) and the “objective” manifestations:

symptoms of sickness (disease) clarifies non-compliance as a confrontation of illness and disease. The patient's subjectivity ("I'm well"), is pitted against psychiatric "objectivity" and particularly the notion of chronicity. If the post-modern experience of illness is partly predicated on the realisation that the subjective experience is beyond the comprehension of the medical model then non-compliance is a clash between the post-modern self and the modernist project of psychiatry.

Shelly often found herself in relatively stressful situations. Not having a successful career was a source of stress for her. Comparisons to her successful sister in the States compounded this stress. For her, stress was also a cause of schizophrenia. Shelly's inability to manage stress makes her susceptible to schizophrenia. One of the ways in which staff at the drop-in helped Shelly was by being overly sympathetic to her stresses that may otherwise seem petty. In contrast to Estroff's view, Shelly sees herself as being well and having overcome schizophrenia. In light of Estroff, what is interesting about Shelly is that she has created a spot for herself where she now feels having overcome schizophrenia, she must face her stresses (get a job, go to school). Yet she is ill equipped to do so because her stresses are ever present as both symptoms and impairments. Stress is potential relapse and underscores the chronicity of Shelly's schizophrenia. In knowing that other people also face a variety of stresses and are not schizophrenic, she cannot deny her sense of dysfunction. Shelly may attempt to refute the accuracy or chronicity of her diagnosis but by relying on stress as an alternative explanation, remains unable to escape her dysfunction.

Throughout my time with Shelly, she seemed to be restoring a sense of continuous self out of the fragments of her prolonged illness. Shelly's continuity is mapped out over her disease. Her illness is the main route by which she has arrived at her current situation and her success is predicated on the management of her illness. Successful management is however not attributed to the success of *working* hard but rather the medication as *having worked*. When I asked her if she is still ill, she says, "no." Asked about the medication she gave the following response:



The medication worked. I always tell myself the medication is there. But if I put myself on the medication I wouldn't help myself in a lot of different ways. I would tell, 'okay the medication helped me do this, do that,' and I wouldn't be able to help myself. I would always think the medication is the one doing it and not me.

Following this I asked if she thought the medication controlled her life.

Well if, in schizophrenic most people, schizophrenics think that medication do control their life. But for me it doesn't do anything but make me sleep and more tired than usual. Now without the medication it seems that I'm doing so good. My life is better. Thinking with the medication and without the medication is like I know for a fact that I'm sick.

Complicating Shelly's struggle to establish herself in the face of, and apart from, her chronic illness is the setting of the centre itself. After the drop-in centre closes, a few times during the week it is occupied by various groups, most noticeably Alcoholics Anonymous. Within the church there are also signs and posters of the religious rhetoric of the twelve-step programme and its reminders of the dangers of drug addiction and dependency. This particular centre also requires users to be members as a way to ensure that members enjoy a familiar environment in which the resources are not stretched too thin. Workers however were also careful to point out that the centre is not a crutch but rather a stepping stone. Shelly, wanting to improve her life and situation, strives to overcome her illness by distancing herself from the centres as a step towards self-reliance. Schizophrenia however is its own predisposition to relapse and Shelly's predisposition is strengthened by chronic stress, itself worsened by denial.

Carlo's non-compliance is centred entirely on a conspiracy theory. He believes himself to be a guinea pig on whom drugs are tested.

They never imported rats in Canada to test drugs so they had to test it on themselves to die from it. So they use people like me to test it.

His diagnosis is a means by which the government was able to have him institutionalised and to seize his money. He disputed the diagnosis remarking that one cannot be schizophrenic and violent.

And I must have freaked out and hurt somebody. But what I know, schizophrenic people don't hurt nobody. They supposed to be scared of people. So [...] there was no reason for me to go to the hospital, or to take

medication for schizophrenic, or manic-depressive or anxiety. They just brought me to the hospital to test me the new medications that came out on the market.

When we first met, it was noticeable how he was having problems finding his correct dosages and suffered several side effects.

The level of the drugs is too high that's why I fall asleep, my legs they get numb from the medication. [...] That's a little too much medication for me. I'm the age of 24: it's not like I'm dying that I need all that medication. [...] but these guys just packs it on, they don't care.

Carlo did go off his medication purposely although I don't think he went off all his medication all at once. When he told me he had stopped his medication, he did indicate that he was still taking his side effect medication. What is significant is that he was selective about which medications he took and that he did not "go off" his medication but rather went "off and on" them. Carlo does not feel schizophrenic but his reactions as side effects of the medications become their own illness. Not taking the medication to control his schizophrenic symptoms, he nonetheless continues with the medications that treat the side effects. Carlo does not make a link from his primary medications through their side effects to the drugs used to treat those side effects. In treating the side effects independently, he presents a unique way of not outright rejecting the diagnosis. Instead Carlo undertakes a treatment thereby misguidedly acknowledging that to some degree he has some sort of illness for which some medication is effective. Carlo never believed in his diagnosis so his refusal to take all his medication is not surprising. What is interesting though is that even when he took some of his medication, he disputed the benefits.

There's nothing wrong with me, so I believe the medication that I take is not for schizophrenic. It's just a medication to uh, if you're drying out, make you shake, nervous. [...] it's just nerves ... like nerve gas in the medication and just a little pump to get you drowsy you know. There's no healing process in medication: there's no healing to be done by medication.

Carlo's theory of being used as a guinea pig, and his prison stories involving physical threats versus hospital institutionalisation involving psychological threats also return us to the body as a site of confrontation between the schizophrenic and other authorities. The body with its brain dysfunction and as a site for the intrusion of biomedical

regimes becomes a small battlefield on which larger political, social and personal wars are fought.

What it may look like to be schizophrenic is part of an understanding of what schizophrenia is.

Individuals with schizophrenia are sometimes physically awkward and may display neurological 'soft signs,' such as left/right confusion, poor coordination, or mirroring. Some minor physical anomalies (e.g., highly arched palate, narrow- or wide-set eyes or subtle malformations of ears) may be more common among individuals with schizophrenics (DSM, 1994: 280).

Just as the DSM alludes to physical indicators of schizophrenia, there is also a pervasive, vernacular conceptualisation of a "crazy look." Side effects from medication and lifestyle habits that manifest themselves as such things as yellow eyes, uncontrollable drooling and being overweight inform this conceptualisation. Being non-compliant can subvert a crazy look by avoiding side effects and as such becomes one way to dispute the diagnosis of craziness. When Shelly spoke about being overweight and needing to lose weight she was expressing her non-compliance as a means to present normalcy through her body. As far as stopping the medical regime is an attempt to be normal by making the body appear normal, it also shows a way in which the schizophrenic not only removes him or herself from the category of being schizophrenic but actively attempts to move to the category of being normal. Non-compliance may be a complaint against the treatment as was Wagner's case, a dispute about the accuracy of the diagnosis as Carlo suggests and/or a denial of disease as Shelly attempts to do.

### Schizophrenia as *de facto* Non-compliance

Changes to the provincial drug insurance policy now require that patients pay a portion of the cost of their medication up front. For those with limited means and a disorganisation that prevents budgeting, buying their medication is often bumped off the list after bills are paid. Poverty is a complicating factor that not only limits the choices of schizophrenics but also subverts adequate treatment for a diagnosis and instead collapses schizophrenia into a collage of social ills. Drug abuse, sexual abuse, unemployment, racism

and criminality segue into schizophrenia as another poverty issue. The Quebec government's new drug insurance programme requires schizophrenics to pay a portion of the costs of their prescription drugs. For one social worker this was a claw back of already limited social assistance cheques.

I think we're starting to see more of its effect. [...] There's people that don't want to take their medication because they don't want to pay for it. They already have a small amount on their cheques, so like, they're deciding between their basic needs already – shelter, food, cigarettes – and now medication.

According to many psychiatrists, failure to take medication is one reason why so many schizophrenics suffer relapses. Various victims' rights and advocacy groups have made it difficult for the police and courts to intervene without going through a long process. Schizophrenia and non-compliance meld together. High hospital returns, relapses and the chronic nature of the illness make the schizophrenic appear *de facto* non-compliant as if non-compliance could be one of the symptoms listed in the *Diagnostic and Statistical Manual of Mental Disorders*. For the schizophrenics however, non-compliance may not be a choice but the most viable option in their situation. Poverty, lack of service/respect at a pharmacy and balancing the effectiveness of one drug where the trade-off is the side effect are all considerations. Being over medicated and treated as merely one patient on a list often makes the patients feel as though the caregivers are unresponsive to their needs.

Shelly is almost desperate to rejoin society from the margins of her illness and in an effort to do so rejects her illness and toys with non-compliance. Shelly has learned however that the stigma of her psychiatric diagnosis will always be with her and threatens the viability of a social role not anchored in that illness. Chuck rebukes our society from his position of marginality yet is forced to acknowledge that he participates. Both people have a lot to say on what are the costs and expectations of fully joining and participating in this society.

One of the most often invoked strategies by *normals* to explain schizophrenia, is a wilful disregard for sanity. Returning to Wagner, non-compliance, for whatever reason, is

one such example of this type of disregard. Severe, debilitating side effects are the cost of sanity. Insanity however is also viewed as a state without the possibility for agency and devoid of culpability.

Part of the sickness role is the associated stigma of the sickness. If non-compliance can be factored into a diagnosis, it can also validate stigmatisation.

Stigmatisation of schizophrenia plays an important role in the development of self and identity for the schizophrenic. Identity is not constructed in a void of self-assertion nor is it the creation of those who surround us. It is a dialogue involving the observations of others, our interpretation of those observations as well as self-reflection and a sense of agency. Stigma is also closely associated in this thesis with a notion of chronicity in schizophrenia. How has the stigma of *having schizophrenia*, of being afflicted or cursed with schizophrenia, slipped into a stigma of *being schizophrenic*? Being ill is usually imbued with a responsibility for becoming ill as well as a responsibility to become well. Being alcoholic is perhaps the best illustration of this point. For schizophrenics the responsibilities for illness and wellness are complicated by the fact that the disease of schizophrenia also implies an inability to take responsibility. Furthermore the responsibility for being ill also blames the schizophrenic for his or her own under/un-employment, homelessness, etc. Making a distinction between illness and self is one of the strategies available to schizophrenics that not only shows an attempt to subvert chronicity but also to overcome (or possibly embrace) different stigmas associated with a diagnosis.

Stigmatisation limits available options and is tremendously difficult if not impossible for the schizophrenic to overcome. When Shelly wonders about prospects for a future husband, she feels that she will have been prejudged. If one assumes that Shelly will remain well enough to marry, then that supposes the prejudice is as much one of her actual diagnosis as of the regime she follows. Stigmatisation is formed in part, if not maintained, by having to keep in contact with a psychiatrist and social worker and having to continue

with medications. Compliance as a constant, conscious effort to maintain mental health reveals to others that something is wrong.

Goffman defines stigma as an attribute that makes someone, "different from others in the category of persons available for him to be, and of a less desirable kind -- in the extreme, a person who is quite thoroughly bad, dangerous or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman 1963: 3).

Schizophrenia seems to involve two types of stigma. The first is that of the mental illness itself. The second is the one associated with homelessness, unemployment, uncleanness, and the other attributes often associated with a schizophrenic lifestyle. All of these are of a less desirable kind.

It is unknown what causes schizophrenia but like other diseases, the disease itself is indiscriminate. Despite the fact that the schizophrenic has no culpability in the disease, general misunderstandings about schizophrenia such as that it is the result of poor family situations or an inability to deal appropriately with stress lay the blame for schizophrenia on the schizophrenic or their social environment. Although the other stigmas of homelessness and unemployment implicate social failings and the inability of our society to provide affordable housing and to create jobs, most people see unemployment and homelessness as individual failings in themselves, not part and parcel of the problems facing schizophrenics.

For Carlo, his diagnosis is the construction of a stigma-theory that is used to explain his inferiority and hence suitability for drug experiments. Although being used as a lab rat may seem far-fetched, it can serve as a useful metaphor through which stigma-theory is used to restrict opportunities by redefining suitable roles. What those roles will be however, are defined by our prejudices, discriminations and the belief that "the person with a stigma is not quite human" (Goffman 1963: 5).

The dominant genetic/biological explanations for schizophrenia have tremendous ramifications for the stigma of schizophrenia. Such theories pinpoint a cause either pre- or post-natally, with a delayed onset. In such a scenario, the schizophrenic has most likely

grown up understanding how stigma works and may have actively stigmatised others. perhaps someone "crazy," only to later be afflicted with an attribute/diagnosis of stigmatisation themselves.

When immigrants state that they didn't even know what schizophrenia was before arriving in Canada, their questioning of the validity of a schizophrenic diagnosis is based in part on the incomprehensibility of its associated stigma role. Diagnosis is one brutal means whereby the schizophrenic is acculturated to this stigma role.

But as far as the diagnosis may also reconfigure past experiences into the development of florid schizophrenic symptoms, it is also the rewriting of a well role in anticipation of a sick role.

When Shelly spoke of returning home, she commented that she was unrecognisable because she had gained so much weight. Equally alienating however, would be how unrecognisable her friends had become. Richard spoke of not wanting to return home because of changes in his homeland since decolonisation. Goffman suggests that learning of one's stigma is a process through which experiences that one shared with friends are re-evaluated and understood as unique in light of the stigma. Shelly is both unrecognisable to her friends and back in her teenage years at the same time. She now understands her past in terms of her present. Her diagnosis suggests that her past experiences were somehow misinterpreted as memories since they could not account for the distorting affects of psychosis. Shelly is in many ways actively recreating a past in her present.

How our social, cultural and political *milieu* may ultimately be expressed in or by a psychiatric diagnoses that undermines understandings of the past is more clearly seen through the examples of the immigrants who moved to Canada and were subsequently diagnosed with schizophrenia. It is equally relevant for all other schizophrenics.

For the caregivers, non-compliance is an indictment of a system which despite all its resources, is unable to meet the needs of those it supposedly cares for.

We offer a lot of support services, such as food, clothing and all that kind of thing, as well as a family-like atmosphere that people will feel comfortable

in. But the people also need psychiatric care. That's often the first step to take in order to help someone stabilise his or her situation. Someone who has a mental illness can rarely live in a stable manner if they are not medicated. You often experience that with this population. One of the major problems we've had for years is getting follow ups for these people because they are often seen as non-compliant by the traditional psychiatric system.

For care givers such as the one cited above, successes are high rates of returns to the drop-in, maintenance of relationships of trust and creating places of safety. This is often in contrast to the measurement of success by the psychiatrist. Not seeing the patient, or seeing them less often indicate the "independence" of the patient. Such independence evaluates the treatment of the disease as successful. How the patient functions with the chronicity of the disease is more pertinent to the patient's handling of his illness (than the psychiatric disease) and thus falls under the purview of the social worker.

Social workers are likely deeply involved with the personal lives of the schizophrenics and the pragmatic problems they face. Finding housing for the hard to house or employment for those with few skills raises some questions about some of the issues created in the void of deinstitutionalisation. When Chuck ran away from the institution he broke a rule (was non-compliant) and was punished. Staying at or running away from the institution were options open to him. For the formally institutionalised, deinstitutionalisation means finding a home and a job. Loss of benefits (no welfare without residency) and marginality (limited financial resources) dissuade homelessness and encourage employment. For Chuck, homelessness as with unemployment for Michael are options newly created in the wake of deinstitutionalisation that may be exercised as part of social non-compliance.

Compliant and non-compliant are two categories into which all schizophrenics can be placed. These two categorisations do not indicate who gets better and who does not nor do they establish even generally, who succeeds with treatment and who does not. Non-response is one possible reason why some people do not improve. Although successful treatment is predicated on compliance, Al Siebert indicates that recovery from schizophrenia is not linked to compliance. He cites Torrey in stating that although one-third of all persons



developing schizophrenia get well. they do so no matter what is done. what interventions are performed or to what degree they are compliant (Siebert. 1999). The medical regime with which the schizophrenic is meant to comply is only effective in treating symptoms of schizophrenia and not the disease itself. Cure, it seems, is not predicated on compliance and appears to be as indiscriminate as the disease itself. It is important then to point out that over a period of time a person with schizophrenia may develop a new/different set of symptoms (Anderson and Olsen. 1982: 789-794). Just as this may indicate the ineffectiveness of current drugs different symptoms may also indicate to the compliant schizophrenic the general ineffectiveness of his current regime.

## **Chapter 10 - Investing in & Redesigning Schizophrenia**

Being schizophrenic or a caregiver of someone who is involves working within and often against a system intended to care for the mentally ill. How resources are managed and goals defined also falls under the purview of this system. In an effort to beat or manipulate that system to their advantage, many schizophrenics use their diagnosis as leverage. Often the diagnosis was redesigned to achieve or justify certain ends. Schizophrenia was most often used to augment social assistance or gain access to restricted services. For caregivers, schizophrenia was a label used to prioritise the needs of individuals and as a means to open doors for increased funding and improved services. This chapter explores ways in which schizophrenia was actively invested in and redefined as a tool for strategic ends.

What schizophrenia is to those so labelled and to those who care for them was often stated during interviews. Caregivers at drop-ins and the users had different ideas about what schizophrenia was but were less concerned with psychiatric jargon than explaining the disease in terms of how it effected them. For the caregivers, schizophrenia determined how resources would be allocated and in which way they would be delivered. For the schizophrenic, the diagnosis offered explanations and although it restricted most opportunities it also expanded different ones. For both the caregivers and the schizophrenic, illness, diagnosis and treatment allowed some opportunities to be seized and other restrictions to be subverted, making schizophrenia a sometimes useful tool. Non-compliance is again a central issue in that when schizophrenia is used only as tool to improve a situation defined by (for example) homelessness and unemployment then non-compliance is part of coming out of that situation. If a schizophrenic believes himself to be using a diagnostic label to get better social assistance then once that assistance helps him on his way, it is easy to understand how he may no longer feel a need to be compliant. If

employment and housing are key goals of reintegration then they are also anchors for non-compliance.

### **Not an Issue of Compliance**

Initially I had expected that those who were compliant would be better positioned to invest in their disease and “pull strings” to achieve their goals. But Glen for instance used limited compliance (four days on his medication, three days off) to maintain access to his drop-in. Carlo would become non-compliant partly because he felt he could work better. Michael and Chuck’s broader social non-compliances were also used to solicit sympathy. Being non-compliant could mean a number of things. Chuck saw compliancy as out of sync with his personal desire to exert and express himself and was synonymous with conformity. For others, non-compliancy was less of a denial of the disease than an acknowledgement that the treatment makes the disease too difficult to be successfully managed by the schizophrenic. Sometimes, non-compliance was a way to confront the treatment as inadequate or too painful but was not a denial of the disease. Compliance and non-compliance are flip sides of the same coin.

*Normals’* constructions of schizophrenia establish role expectations. Meeting or failing to meet these expectations is often explained in terms of non/compliance. However, as Estroff noted about conceptions of schizophrenia, non-compliance also means a lack of competency and culpability:

The loss and disorder of person so characteristic of our conceptions of schizophrenia may be at least partly of our own invention, and one of the many ways in which we beset the person who has schizophrenia (Estroff, 1989: 96).

Some of my interviews illustrate that as states of being, contesting and accepting the diagnosis were more of an ebb and flow than static and involved exactly the expression of competency (to manage their own affairs) that seem to be denied to them. Shelly for instance is both schizophrenic and well. This contradiction, aside from the ramifications for compliancy, shows how she has accepted her diagnosis and the longevity of the disease but disputes its chronicity as recurrence. Shelly is also a good example because part of her

being proactive is her understanding her diagnosis, what it is to be schizophrenic, while it seems that part of her being better, is understanding herself not as schizophrenic, but someone well although susceptible to stress. So long as she feels able to manage her stress there is little need for the medication.

Carlo on the other hand, selects his drugs but does not refuse all of them outright. Although he would not say that he is schizophrenic, his sort of managed non-compliance provides a possible example of how one could accept a diagnosis while contesting the treatment as one designed for specifically for schizophrenia. Carlo accepts a diagnosis of some sort of mental illness, but not schizophrenia.

Chuck provided links between a larger social critique, the diagnosis and the exigencies of schizophrenia. In many ways he indicates how his sick role is nothing more than a well role that has been deemed unacceptable. Chuck redesigns his schizophrenia as a sort of uncommon behaviour or personality type and reconfigures compliance in terms of conformity.

Finally, a division between those who contest and those who accept a diagnosis is not geared towards their carers (non-psychiatrists) whose understanding of schizophrenia, while obviously impacting on the schizophrenic's acceptance, was often invested with ulterior motives. Maintaining order in centres, augmenting benefits, finding affordable housing and improving the chances for permanent residency status where some of the tasks of social workers. In each of these cases, being labelled as schizophrenic aided access to specially designed programmes and services. Even if schizophrenia was poorly understood, its label was useful. The St. Thomas with its mandate to care for the mentally ill is a case in point. Schizophrenics through the centre are provided food bags, a social network and may be placed in special housing for the hard to house. Schizophrenia has an associated utility.

### **Lay Psychiatry**

Most people have upon occasion referred to someone as "crazy", "a psycho", or any number of other lay psychopathologies. This may be an example of how psychiatric

diagnoses as jargon have become part of daily vocabulary. For non-psychiatrists who care for the psychiatrically ill, there is more at play here than expanded vocabularies. Just as elsewhere this thesis has illustrated a withdrawal of psychiatrists from care giving, there is an infusion of psychiatry's jargon into care giving. Social workers and others, in constantly being asked to evaluate people and situations, deploy psychiatric explanations for their observations.

The following quote is from one CLSC worker explaining what she likes about her job. Melissa also shows the overlap between professions, specifically in social work and psychology, and generally among the "helping profession."

...my background isn't social work; I don't have my BSW [Bachelors of Social Work] yet. As a matter a fact, now I am studying in psychology as probably the field I will be going in. But I got involved in the work, started off as stage. I was interested in the helping profession. And then it was a matter of just fun um, you know, staying in it, and just, uh, liking it and the dynamics of the community organisations. I've always worked in the community. I haven't necessarily worked in what we call "*réseau*" [network]. Uh, I've always stayed in the community because I like the dynamics, I like the frontline work, and uh, that's just the kind of frontline work that I like to do.

This quote is also interesting for its contrast of frontline community work with the network of professionals in the "*réseau*." Melissa, like other caregivers in the community, portrays the community as a place where one gets one's hands dirty. Often, invoking "small", "community" or "personal" approaches was key to defining the work of smaller centres. All the workers however also spoke of a network from which they were able to draw support and more importantly information that would be otherwise confidential and inaccessible. By drawing a distinction between the frontline and the *réseau*, Melissa also draws epistemological distinctions. The community does not employ clinical observations as part of its assessment of individuals. Even though many users of a drop-in come in with a diagnosis, it is rare that the centre would know this diagnosis. As a potential user of community services leaves the *réseau* he may undergo a second evaluation that makes his needs clear to the community-based carer. People who show up at the door of the St.

Thomas for the first time are evaluated to see if they fit with the centre's mandate to care for the mentally ill. Joanne elaborated on this informal process.

Well, we know all the members, so as soon as someone new walks in, we, like in the first, you know few minutes, or half an hour, one of the staff talks with them, and we, you know do a little interview with them and from the interview we can usually determine if there is a mental health problem. Finding out who told them about the centre, why they've come to the centre where they usually go, like what were they doing before they came to the centre, how were they meeting their needs, you know, to see if they have other, other resources they could use.

Joanne's interview of someone new is meant to informally pick up clues about that person's mental health. The fact that the person is unknown to Joanne means that there is little room for personal eccentricities and idiosyncrasies to account for odd behaviours. The highly informal assessment picks out how this person is using other resources and if there is possibility for them to use some of her centre's resources. How the person arrived at the centre becomes key to establishing whether or not they have a mental illness and are eligible for help. Coming to the drop-in for a meal from the welfare office is not as consequential as coming for a meal after release from the Douglas Hospital. This sort of informal evaluation outside of the *réseau* relies on assessing the post-intervention treatment. What this means is that once outside of institutional care, symptoms of mental illness, behaviours, life situations, the manifestations of side effects are closely associated and all meld into signs of mental illness. Another worker at a CLSC said this about evaluating people:

We wouldn't say definite that this person is suffering from so-and-so. We would say that it appears, you know, given that this person may have some sort of psychological problems, psychiatric needs, some kind of evaluation. So you would say that this person is suffering, what the person is doing or not doing, that sort of thing. But we are not doctors, we cannot make medical diagnosis and we can't make really psychiatric diagnosis as such [...] There are some cases that are very straightforward. You can see the person and straight we've brought them to the hospital or make a crisis and take them to emergency, you know, we send them or take them to the emergency or whatever. But there are other heavy cases that so many other things are intertwined, family situations and comfort problems that we discuss it here with them.

In the previous chapter, non-compliance was linked to confusing certain normal reactions (anger particularly) as behaviours ("disruptive") associated with a schizophrenic

symptomology. Disruptive behaviour may be an indication that the user has gone off their medication but if the workers know the routine of the user, it may alternatively indicate compliance. Daily stress combined with the psychotropic drug regime may produce disruptive behaviour. For the workers this behaviour is distinct from simple bad temperament. How this distinction is understood is unclear but it has something to do with the spontaneity of the behaviour as well as the cyclical nature of the schizophrenic treatments. One social worker, Beth, observed, "Sometimes even the day they've had their injection it hasn't sort of kicked in. So they're still sort of difficult."

Since at Beth's centre, users are informally evaluated by talking to them and watching them interact, the use of disruptive behaviour as an indicator of mental illness relies on the relationship and familiarity of the worker with the user. One social worker spoke about the need for a non-judgemental involvement based in active listening. Establishing rapport was central to a relationship.

Active listening would be number one. Active listening involves, um, it's um, when you talk about active listening it's not just listening, it is really being there, being involved, empathy, um, understanding, uh, going through the, uh, it's non-judgemental.

Knowing the schizophrenic is essential to treatment but not feasible as part of the informal evaluation that assesses eligibility to that treatment.

### **Adjectives and Descriptions**

With specific reference to schizophrenics other words used to describe them were, "slow", "lethargic" and "disorganised." Another symptom for them as well was a state of dirtiness.

A lot of schizophrenic people are, are dirty to look at and to smell and they don't even realise it. They're, I don't know how they don't realise, but they don't. They don't know that they're dirty, they don't know that they smell bad.

Because of their illness, they just don't think that they're dirty [...] It doesn't even occur to them that they're dirty.

Several things emerged from such descriptions. Again there is a feeling that these descriptions are temporally comparative. "Slow", "lethargic" and "disorganised" imply

a pre-schizophrenic (proto-schizophrenic) that was quick, active and organised. Such a schizophrenic is unknown to the worker and so for others what may be character attributes are signs of psychiatric problems. That they are dirty was one description I heard (and heard contradicted) several times that surprised me. It surprised me because it seemed to me that the vast majority of centre users were clean even though I'd have to admit that it was the dirty ones who left the most indelible impressions. Making sure that all users were clean was a priority for all the centres. One social worker challenged the idea that schizophrenics were dirty by saying that being dirty was a defence mechanism used to keep people away and was just as easily linked to other groups of marginalised people such as the homeless and criminal. What one social worker assessed as a strategic defence mechanism, another assessed as an indicator of psychiatric illness.

The descriptions of slowness, lethargy, disorganisation and dirtiness of the schizophrenics were intriguing because even as workers used these descriptions their falseness was being made evident. Some schizophrenics couldn't sit still, couldn't stop pacing, and spoke a mile-a-minute. All of them navigated the system of health services and community programmes in a highly organised manner, walking several miles a day to do so.

At the same time, and aside from the effects of medication, slowness, lethargy and disorganisation were also partly a result of using these community services where basically lots of snacks, a television, and a couch made users appear unmotivated, slow and lethargic. The space of centres at times seemed designed to hang around in while snacking before meals. The staff, in maintaining files and medical updates, removed a need for the users to be self-organised while at the centre. In fact, part of using a drop-in seemed to be the relinquishing of control over these matters. For many, organisation was proved in other ways. For Michael this was keeping his appointments for injections and taking care of his daughter. For Shelly it was work. What the centres' staffs organised were often details that showed the differing priorities of their users and ought not to be seen as indicative of lacking ability. Shelly needed her budget to be managed, but not her appointments or even



her meals. Michael needed his mealtimes and groceries organised but was able to keep his appointments. All the above descriptions, including being dirty figured prominently in treatment/therapy as well. Showers, field trips and keeping appointments were essential to a treatment with reintegration as its goal.

Disorganised symptoms were included as indicators of schizophrenia and show how psychiatric text slip into lay usage without the original meanings. Staff would not define disorganised symptoms as "derailment", "circumstantiality" or "illogicality." Doing so would exclude a number of schizophrenic users such as Shelly, Michael and Richard. Considering that most of the schizophrenics the staffs selected for interviews were clear and cogent, disorganised symptoms seem well treated among the schizophrenic users. Staff seemed to be associating disorganisation indirectly with schizophrenia through recreational drug use. Being stoned was common for many drop-in users just as homelessness and unemployment were common situations. Shelly was employed when we met, had a home and did not take drugs yet as a user of drop-ins can easily be associated with all of those. Complicating this were the glazed, yellow eyes, a common side effect, and a sort of dragging slowness of her weight. In any case, being stoned from marijuana, drunk or high on crack has no association with schizophrenia itself. Drug use is however associated with non-compliance. This provides another point of access since non-compliance has obvious associations with schizophrenia. Compliance, non-compliance, pharmaceutical and recreational drugs are often blurred by circumstances and in understandings making drug use and drug treatment difficult to distinguish. One schizophrenic had spent time in jail for assault. A condition of his release was that he commits to complying with his drug treatment. Whereas workers had understood this as a commitment to follow his treatment for schizophrenia, users understood this as a commitment to stick with a drug treatment programme that would get him off cocaine.

In general, disorganisation seemed to be part of what filled the void of institutionalisation. The staff took being organised for granted among normals not seeing it as a learned skill perhaps atrophied from institutional care.

Disorganised behaviours as witnessed in unusual clothing, appearance and social and sexual behaviours is also more closely related to a situation than a diagnosis. Clothing is given out at some centres and articles bought from a thrift store are best chosen for functionality and price than appearance. One man at a residence was embarrassed by the T-shirt he had been given to wear that day. It was black with a large pink triangle and a gay pride slogan emblazoned on it. Odd social and sexual behaviours seemed part and parcel of places where for instance a withdrawn man's limited social network is forged amid street workers and other equally withdrawn users.

Investing in a sort of system was one way in which some carers and schizophrenics explained what was going on in a way that was beyond their control. Acknowledging a socio-political system that seemed to be controlling a diagnostic label, treatment, institutionalisation and care was inescapable. Surrendering power to, or drawing authority from, that system however was a key strategy in negotiating roles. In Mathew's confrontation with the social worker (see page 99), both were using a system to negotiate roles. Mathew tried to draw on a system to protect his legitimate right to privacy and to assert his individual agency. The social worker drew on a system to exert authority and invade Mathew's privacy. How schizophrenics and caregivers invested in and divested themselves of a system formed part of their social critiques and commentaries.

First of all, investing in or not investing in the system was largely decided by believing in or not believing in the diagnosis. To "believe" also denotes a feeling of "faith" – as a sense of certitude or assurance. One may have faith (or not have faith) in a time, *milieu* and system that has created place for such a diagnosis and an associated role. Michael expressed this sort of faith when he notes that his diagnosis was only possible in Canada where the doctors know about such things despite the fact that he can trace

symptoms to childhood in the Caribbean. Michael's story is anchored by a reliance on (a faith in) the welfare state and the medical system. Secondly, there does need to be an exploration of some of spaces in which a non-psychiatrist could adopt a belief in the diagnosis of schizophrenia as a disease, an excuse and/or a useful tool for administration without necessarily understanding or accepting its symptoms as legitimate. Lastly, there is the potential for tension and conflict within a schizophrenic who although believing in his diagnosis cannot believe in a society which marginalises him because of that diagnosis but whose treatment is dependent on his reintegration into that society.

### Workers' Investments

Throughout the research involving centre workers it appeared that part of their dedication was based in a belief of a better world. As advocates they believe in a better situation for the marginalised in our society: their vocations were investments in a system stemming from a desire to affect change. Faced with budget cutbacks, they contrasted the wealth of our society with extreme poverty and marginalisation. Workers believed in society, its ability to change and the opportunities it held for everyone to participate. Social problems were windows into all sorts of mental distress.

Mental distress, and I'm not just talking about mental illness is quite high. People are having a hard time getting by. U'm, and there seems to be a lack of uh, just a collective support network in an individual's personal life. Okay, people are not connecting with other members of the family, maybe because of divorce, maybe because of separation, maybe because, you know, the family disintegrates, at some level, people are not connecting with other people at work, but then again, less people are working. So you do find, you know, there's a link there, you know, between, the social context of our society, and the kinds of problems that people are experiencing. So yes, the increase of mental illness is quite high.

They also were heavily invested in psychiatry. Often faced with someone having been just released from an institution and literally dropped off at the centre, they saw a need for psychiatry to treat people and an aptness in its diagnosis. For many workers, the users were simply mad and legitimately diagnosed as so. Although no worker would suggest that a diagnosis of mental illness be used to restrict social participation, such diagnoses were invaluable administrative tools to effectively facilitate that participation.

The label of schizophrenic was readily deployed when outside involvement was needed. The few times that the police were called to a drop-in, the understanding that someone with a mental illness was involved facilitated their speedy responses. When assertiveness and aggression can be misunderstood as a symptom then even while the legitimacy of that symptom is undermined, it nevertheless becomes an important tool to deal with (sanction) the schizophrenic. Getting hospital records without consent was another way in which carers achieved an ends that would not be possible to perpetrate on *normals*. Getting the records of a schizophrenic was easy because the carer could use schizophrenia as a password, another administrative tool. Centres that needed their funding renewed yearly maintained statistics on the number and type of users and used the rise in numbers among the mentally ill as an argument for more funding.

### **Schizophrenics' Investments**

People living with the diagnosis of schizophrenia, were their own experts. An individual schizophrenic's attitudes towards other schizophrenics and schizophrenia shared similarities and dissimilarities with others' attitudes and accounts.

For the most part, they were many consistencies. Schizophrenics were determined to exercise options and agency of which choosing where to eat and what medications (if any) to take, are two examples. Schizophrenia is manifest in a variety of ways with symptoms differing from person to person. Although schizophrenics have largely adopted the psychiatric jargon of their illness, key understandings of what they are (as those diagnosed as schizophrenic) as opposed to what schizophrenia actually is, was one of the most poignant descriptions to emerge from their narratives.

I'm schizophrenic. They said they diagnosed me schizophrenic, say I hear, trying to kill me, because I hear someone's trying to kill me, I hear voices, you know, people. I hear voices. [...] and I get paranoid.

Although this informant relies on two symptoms (hallucinations and paranoia) to justify his diagnosis, it is unclear as to whether or not he clinically understands these.

All the schizophrenics interviewed were aware that they had a problem. It may be that they were being persecuted, that they were unable to live independently, or perhaps that they were unfulfilled and felt cheated by the hand that life had dealt them. An awareness of a problem that others did not seem to have or that others were not plagued by was consistent among schizophrenics. Henri used a common alcoholics anonymous analogy about always crossing the street on the red light. Part of this metaphor is the need to control a sort of "living on the edge."

I'll tell you what happened, is that I ... I ... I didn't cross a red light from 1969 to 1989, you know? I found that in 1989 I'm selfish [...] because I don't care you know, a red light, people walking by or cars or what, you know. So I said to myself, I'm going to try and cross at the green light and I did from 1989 to 1991. I was 31. [...] What am I -- who am I trying to fool? I'd like to cross green lights you know but I said to myself maybe I'm, you know, under pressure, so I cross on a red light and a car just came, you know? Just like that and I ... I just stopped in time and I kept on crossing the red light...

Although this may on some level indicate how schizophrenia is manifest in him, his limited ability to function is equally part of his diagnosis.

I can't take care of myself because I can't uh, cook, buy groceries, buy telephone, pay the electricity, shop uh and uh cook an' uh, make the bed, wash the dishes, do my laundry.

Schizophrenia is the reason he cannot live with his ageing mother, yet Henri also realises the irony of his lifestyle and the policy affecting it. "You can't live in a hospital forever," he said.

All schizophrenics from the moment of diagnosis have a problem. Onset of psychosis, hospitalisation and the demands of the medical regime mark periods of rupture, stigmatisation, dysfunction and marginalisation. Diagnosis represents a watershed separating the life and potentials they once had from the life they are reconstructing and the circumscribed potentials it seems to provide. They may believe themselves to be well or to have another illness or problem but the diagnosis of schizophrenia has altered their lives by virtue of rupture. A sense of rupture was commonly alluded to during interviews with poverty, unemployment, interrupted studies, homelessness and estrangement from family

and friends, its key axes. Eddie's story, as the residency's staff told it, was that his family (all in Montreal) refused contact. He became homeless and lived on the street for several years before pneumonia forced him into a hospital which later released him into the residency with his new diagnosis. Such a rupture is a derailment from which one is never certain of recovering. Although Shelly may feel she can recover from schizophrenia, she increasingly feels too old to go to school. "Youth's greatest disabler" has stolen years of her life. Schizophrenia explains a derailment that can be used to account for future failings or shortcomings.

Secondly, and following from this, is a recognition of the stigmatisation of the illness and a sense of liminality which this involves. They know they are marginalised and have only a slim chance to overcome this. In this sense the chronicity of schizophrenia and the chronic, cyclical nature of the schizophrenic's situation are tightly woven together. In the words of one schizophrenic, "schizophrenia is a life sentence." One caregiver agreed with the metaphor.

I think that psychiatric problems like that, are for life. You don't get over them. Mental illness, once you're, once you're determined schizophrenic, diagnosed schizophrenic, you have schizophrenia for the rest of your life.

The metaphor of a life sentence is particularly good for those who felt that the accusations are untrue and the conviction unfair.

...since you become underneath the psychiatry, it's like you've been sentenced for 120 years of your life, 'cause psychiatry medication is forever, it's a sentence that the government passes on, that you must take medication for the rest of your life [...] you must take it, no matter what. If you don't take it you must be hospitalised. [...] It's a punishment.

Thirdly, all the schizophrenics believed, at least somewhat, in a system. This system may be there either to offer support or was part of a conspiracy theory. In either case there was a system with direct impact in their lives. This system, as part of a conspiracy theory was most often invoked by the use of "they" specifically in reference to whomever administered the medication. Again the images of guinea pigs returns as in the following quotes by two informants.

“They test something on me and after they test it on me, they tell me I’m a schizophrenic, and I’m manic depressive.”

“They’ve been trying out new medication on me for my, my sickness.”

Furthermore, augmenting sick benefits was one of the most common ways in which schizophrenics involved themselves in the system. Welfare as part of the system also played a role in explaining schizophrenia or validating its acceptance. “I’m trying to get more money out of welfare, that’s all.”

Fourthly, there seems to be a denial of the chronic nature of the illness such that all schizophrenics either believe themselves to be well or look to the day when they will be well. This is a significant result of cyclical treatment and the revolving door of the hospital. Either as soon as they are released from a watchful eye or feel themselves to be well/cured, schizophrenics stopped taking their medication and restarted the cycle of intervention and hospitalisation. Shelly’s quote offered particular insight.

The medication worked. I always tell myself the medication is there. I ask [my doctor] if he could please turn the medication a little bit down, lesser doses -- and even some days -- maybe I could skip some days. [I’m still wondering] whether to stop it or keep it on a low profile.

Finally, they all seemed to agree on some clinically defined aspects of schizophrenia whether or not they believed themselves to be afflicted by it. This most certainly arises from their exposure to clinical definitions of their diagnosis but did not involve an analysis of their life story. “I [they] hear voices”: “I [they] get paranoid”: “I [they] withdrew and spent days in my [their] room”: “I [they] lose my [their] attention span”.

What some schizophrenics thought about others also offered insight into how they understood schizophrenia. It was also often the most apparent way for the informants to distance themselves from others. Two informants gave the following quotes about others:

They’re okay! But they’re still lacking. They lack responsibility, man. They have no responsibility, you know? They don’t realise what life is all about.

They’re sick, they’re sick from the medication! Medication burn their brain and make them become worse...

Lack of responsibility, disorganisation, ineffective treatment and conspiracy theories clarify a particular route for which schizophrenia is the end and culmination.

Even if some have moved on to where they are "better," they may have at one time believed in their diagnosis and as part of their therapy, saw social reintegration as essential to recovery. They are striving to rebuild their lives. This is done by maintaining close contact with a psychiatrist and other health care professionals. However, remembering that follow-ups are hard to come by for most schizophrenics, this rebuilding is difficult and requires a certain vigilance. Part of the process involves negotiating medications. The patient may deny information to the doctor or fabricate stories to alter or eliminate medications as they "get back on their feet." Since, almost always, mentally ill patients are initially over medicated then slowly cut back, manipulation of the treatment is learned and used easily by the patient. "I'm better now" or "I don't need the medication anymore" were common remarks made by some schizophrenics in this situation. Shelly's quote illustrates this point.

[The medication] doesn't do anything. [...] It makes me feel very very tired. And I eat a lot. I eat and eat and eat and never want to stop. [...] Now without the medication it seems that I'm doing so good. My life is, is better. [...] I feel normal. I feel I have a lot of energy. I feel like I can go anywhere. And I feel very very happy.

Believing in the diagnosis was part of investing in society and one feature of this belief was often the view that system was helpful and supportive. This led to the forging personal relationships with social workers and/or psychiatrists/doctors. Some schizophrenics were eager to work and saw this as a way to break out of a role weighed down by social assistance. This was also the point in which stigmatisation most clearly insinuated itself as was case when Shelly was fired.

Generally schizophrenics could pinpoint moments of rupture in their lives and made distinctions centring not around before and after diagnosis, but between adulthood and childhood. Although this may coincide with before and after diagnosis, there are two distinctions to be made. Firstly, for the schizophrenics there appears to be a few years



during which they knew there was something wrong, but had not yet been diagnosed or realised the problem as one involving mental health. Secondly, a state of being mentally healthy overlaps with or is confused for childhood/adolescence. This period is not necessarily one of time but of nostalgic reminiscences of the "good old days." Although hearing voices, paranoia, and hallucinations may mark the illness, school, dating, and living with their parent(s) punctuated wellness. Shelly again:

...five years being treated on medication of schizophrenic. I feel good in the sense that I'm back in the age of seventeen between sixteen to seventeen but I'm doing good. [...] My life changed. Like back again, since I'm 36, from 17 years I skipped 24 and woke at 36 understand? It's like I'm living in a state of the same that I know myself before the relapse.

Shelly's desire to return to school is part of a return to this period of her life.

Schizophrenia as "youth's greatest disabler" also hints at the loss of youth. Adulthood with its own responsibilities or the transition to it with adolescent upheavals help to depict youth and childhood as free, innocent and full of potential. This is opposed to the liability of adulthood.

The diagnosis itself may offer a schizophrenic a way of understanding a problem and obtaining proper intervention. The diagnosis of schizophrenia at this point seemed to offer more opportunities than restrictions.

This opportunism was most apparent for those who had exhausted family resources and saw the diagnosis as potentially offering either a way out of a criminal trial, a bed and meals and/or increased social assistance. Michael who was arrested for a mugging spoke about such opportunism. Too high on marijuana to fully understand what was going on during his arrest, he is unable to remember if he stole the purse. For him though, this is not the issue since the arrest meant a place to stay with meals, while the diagnosis mitigated the exigencies of prison as well as the court trial, offered him medication, increased help with immigration and augmented welfare.

...The cops lock me up, saying [...] that I ripped off a woman's purse. I have no money on me, nothing on me man. [...] I was freaking out man. My hair was all crazy and they locked me up man. They say it was me. But now, I'm sure they helped me, you know? [...] I said I want to go to the

hospital, so they send me to the hospital. And there they start giving me the right treatment, telling me I was schizophrenic, you know. [... It] was a nice place, you know? Two showers a day. Two showers a day, you change your pants, your jeans twice a day. Morning and afternoon. They gave medication. [...] Me got a radio and me hear the radio you know?

When schizophrenics attempt to use the system, they often become trapped into constantly accepting help and rationalise this as advantageous. Money is not saved, but rather spent either on drugs, or at places such as Dunkin' Donuts. In this way, the diagnosis and the psychosocial help that comes with it drive personal motives. The goal of obtaining more money relies on a diagnosis. Once the social assistance is augmented however, responses to the diagnosis (the help and treatment) are reconfigured as intrusive. Their treatment is less a process of learning and coping than it is of resistance and pretending or fooling to pass through the circuit. Denying their diagnosis can be outright or shrouded in the mysteries of hospitalisation.

One informant said his hospitalisations were for "scalp itch", his wisdom teeth and corns on his feet. However bizarre the hospitalisations may seem, his treatments would seem equally so. "Um, surgeons, neurosurgeons, uh, let you stay in the hospital. [...] They just, you know, sleeping pills." This particular informant was known to spend most of his social assistance cheque at the Dunkin' Donuts, ordering the breakfast special all day long. He was one of the many that asked for help improving his social assistance.

Often what constitutes mental health, health in general and the side effects of the medication are confused by the schizophrenics and as such the metaphors they use rely on normal imagery but remain bizarre because of their misplaced contexts. When asked what mental health was, one informant gave this clarification. "Mental health means uhm, mental health means, uhm, eye glasses or operations for my eyes, eyesight."

Michael also offered good examples of how schizophrenia was understood through the lived experiences of side effects, misinformation and habits:

I hear people talking to me, or my foot starts jumping or I do that [shakes his arm], or I start freaking out at little things, you know? Or me before I started taking my medication, I used to come here and be ignorant with everybody.

Sometimes I'm drifting and spit come out of my mouth and things like that.

What it mean? Split personality, I hear thoughts, uh, you shake your foot. You know, smoke a lot of cigarettes.

Michael's examples of what schizophrenia is and how it is manifest show how his living with schizophrenia, popular understandings of schizophrenia and the clinical diagnosis converge. Physically, Michael does not distinguish between side effects of the medication and the disease. Non-psychiatrists often regard "split personality" as part of the clinical diagnosis yet is not part of schizophrenia. Split personality is another disorder confused in popular culture with schizophrenia in the media. Behaviours, compulsions and marginalisation round out Michael's understanding of his disease. When he indicates however that he used to be confrontational ("be ignorant with everyone") before taking his medication he also uses schizophrenia to explain unacceptable behaviour. Schizophrenia as an excuse fails to explain why Michael would "be ignorant with everyone" yet other schizophrenics socially withdraw. Michael balances the utility of schizophrenia by alternatively using it as an excuse and an opportunity. Schizophrenia, as Michael's descriptions and life history indicate, is an opportunity to improve social assistance benefits, to avoid working and to mitigate jail sentences as well as to explain past deficiencies and prove his responsibility.

Schizophrenia is more than a psychiatric diagnosis but even within this confine, it has many interpretations as the lives of schizophrenics are played out. This playing out allows the user, the psychiatric patient, the non-psychiatrist carer and a range of other actors to rewrite their relationships and renegotiate their relationships. Often at odds with one another, there is significant overlap and agreement. Community services and the people staffing them provide a place for these identities and descriptions to be thrashed out. Employment and having a home are important anchors for the development of a viable well role. As Chuck points out though these anchors are not indispensable to a well role. His well role is predicated on his ability to maintain a sense of self despite conformist pressures.

Resisting a home is one refutation of the exigencies of being well. It also implies getting lost in a system that (for example) needs a permanent address to deliver social benefits. Schizophrenics and their caregivers inevitably find themselves working in, with and sometimes against such system. Welfare, justice and mental health systems are parts of this larger system and the parts with which schizophrenics and carers are most in contact. Schizophrenia as a useful tool to administer over a group of people acknowledges this system as an investment in the authenticity of disease labels. Using schizophrenia to improve assistance is a strategic investment in the disease. Non-compliance, purposeful homelessness, and unemployment can be a means for withdrawal of support from the system and a denial of disease.

## Chapter 11 - Conclusion

The research project that facilitated this work was my first introduction to schizophrenia and schizophrenics. Although I spent several weeks trying to understand the goals of the project and undergoing a sort of training, I was unprepared for the multitude of questions I would create for myself in the pursuit of answers. Pursuit of answers to my original question of what is it like to be schizophrenic seemed only to create more questions and barriers to finding answers.

None of my interviews were primarily concerned with internal brain processes and chemical imbalances but rather entire lives that weren't lived with schizophrenia but as schizophrenics. Schizophrenia became less and less a disease and more and more a whole identity fraught with role defining tensions.

What is schizophrenia? A brain dysfunction manifest in a variety of symptoms of which psychosis is the most evident; an administrative tool for managing a group of people diagnosed as mentally ill; or an expression of social valuations of behaviours and morality. Persuasive arguments can be made for each of these understandings.

More than just an opinion about these understandings, throughout this thesis, I offered a different approach that views schizophrenia from the perspective of schizophrenics and those primarily responsible for their care. What is it to be schizophrenic and consequently viewed as psychiatrically ill (afflicted with a brain dysfunction), a member of a group administered by a range of professionals and/or stigmatised with an evaluation of behaving oddly? What are the consequences of being treated as all these things? How does one create a viable sense of individuality amid the expectations of the roles these understandings anticipate and how does one dispute such understandings and/or those anticipated roles?

As an answer to what is schizophrenia, I would argue that more than anything else it is a diagnosis manifest in life; it is a situation which each schizophrenic attempts to shape

and is shaped by. This thesis simply illustrates what schizophrenia may be by offering a selection of narrated vectors that schizophrenia, as a situation, has taken for a few schizophrenics.

What it is to be schizophrenic can be viewed from a variety of perspectives. Each of these perspectives are in turn informed by particular values, systems and policies pertinent to a time.

A shift to hermeneutics and an acceptance of the post-modern experience of illness are two such epistemologies expanding the options among perspectives. Both of these epistemologies involve studying meanings beyond a diagnosis and understanding that there is more to the diagnosis than the diagnosis itself can explain. The experience of living with schizophrenia goes far beyond the affixation of a psychiatric label to an individual.

Schizophrenics are schizophrenic in a particular time. Deinstitutionalisation, as an effort of our time, has allowed schizophrenics to be returned to the community. On one hand this has been empowering for them even as it presents them with the difficulties of finding housing, employment and making friends. It has allowed them greater control over their lives and the management of their illness. On the other hand, our time is also one in which control, power and surveillance have been deinstitutionalised. Their omnipresence has meant that schizophrenics in the community still face a range of controls that replace psychiatric conformity with a more pervasive and equally rigid social conformity.

The withdrawal of psychiatry from the immediate line of care of schizophrenics has left the diagnostic category of schizophrenia increasingly an esoteric theory that fails to address the reality of living with abnormal or disordered behaviours and thoughts. How to maintain the integrity of a diagnosis with symptoms manifest so variably in different individuals and with several exceptions is one problem elaborating the psychiatric paradigm. But just as the categorisation of schizophrenics is eroding, medical advancements that treat symptoms are driven by pharmaceutical concerns and the daily problems that schizophrenics face are mitigated by caregivers. Deinstitutionalisation as either voluntary or

involuntary admission to short term acute care hospital stays from a few days to several weeks has replaced the long term asylum bed and care facility. In many ways, deinstitutionalisation has meant that the schizophrenic, freed from the institution is also removed from the scrutiny of psychiatrists and other professionals more generally. Interventionist forces such as the police and courts, social workers, emergency room workers, drop-in centre staff and family mitigate the schizophrenics' everyday existences. Being less susceptible to the invasive, forced treatments of institutions has meant that non-psychiatrists are increasingly caring for individual schizophrenics while the disease of schizophrenia remains staunchly under the purview of psychiatry. The disease is administered by psychiatrists while the illness, or subjective experience of the disease, is managed, and otherwise relies on treatment by pharmaceutical companies and non-psychiatrists as care givers. Shifts in management and care are one example of how authority and power, more than the psychiatrists themselves, have been deinstitutionalised.

The ex-inmate of the asylum is the product of deinstitutionalisation and not the result of a cure or the mitigation of chronicity. Nonetheless, schizophrenics are forced to cope with their disease and the stigmas associated with it. Manipulation, denial and non-compliance are perhaps not an expression of coping with the disease, treatment exigencies and stigmas but rather a confrontation of them. Claiming not to be ill, to be cured or well and to refuse the treatment are strategies used to dispute the diagnosis and to deny the authority of those who made that diagnosis. Denial and non-compliance are closely associated to relapse and the onset of florid symptoms. These strategies then can be seen as inextricably linked to the disease itself. Non-compliance can also be viewed as a by-product of deinstitutionalisation. Predicated on the assumption that patients accept their diagnosis and will voluntarily follow their medical regime, deinstitutionalisation allows for wills to be exerted and treatments avoided. Conflicting expectations about the efficacy of treatment, side effects and the feeling of wellness are all possible explanations for non-compliance as a form of expression and agency.

Many of the mentally ill are wards of the state and/or have their finances administered through a social worker, an institution or the public curator. This is where social theory becomes reality: the goals of public policy intersect with lives and mandates attempt to meet needs. Mental health care is a complex web of interactions between government agencies, users and providers. The intersection, indeed collision, of private troubles and public policy is a point of access for understanding the shortcomings of such policy. At the same time however, public policy is an amalgamation of resources, culture and history while psychiatry itself is the product of a certain social, cultural and political *milieu*. Public policy validated by psychiatry enforces a vicious circle that attempts to administrate over a mental illness while not addressing the situations in which this illness manifests itself as lifestyle: it seems to operate as a tool out of context. Public policy deals with general organisms, not specific individual agents and yet treats problems individually rather than interrelated. For example, schizophrenia is one problem and homelessness another. Public policy regards schizophrenics as mentally ill above, beyond and before issues such a marginalisation are addressed. At the same time the architects of such policy fail to see schizophrenia as individually manifest and a social phenomenon with a lot to say about declining social structures: networks, the economy, social welfare and cultural prohibitions.

Quebec's *virage ambulatoire* is the government's policy shift from institutionalised care to community-based care. The *virage* itself is obliquely part of an attempt to balance changing attitudes with technological advances and to cut expenditures. It is also an effort to change the way services are delivered and by whom. Although this shift is meant to involve the establishment of more and improved community-based centres, so far the *virage* has mainly been effective in advancing deinstitutionalisation.

Deinstitutionalisation is currently the primary force informing/reforming our views of what schizophrenia is. Deinstitutionalisation has brought many people closer to schizophrenics who now live "at large." Its failures have also meant the collapse of social



problems into the symptomology of schizophrenia. Deinstitutionalisation conceptually encases a broad range of our socio-cultural values while expressing major underpinnings of our health care, justice, and welfare systems, as well as public policy initiatives. Release from an institution is ultimately the goal of deinstitutionalisation. Institutionalisation however is about treatment, custody and structure. Deinstitutionalisation does not leave a vacuum and in fact relies on community-based centres to achieve the same goal. It then begs the questions into what are the psychiatrically ill being released and equipped with what coping tools? To link institutionalisation and deinstitutionalisation is also to indicate that responsibility, who dispenses it and who gets it, is driven partly by economic concerns. Asylum bed closings, the increased professionalisation of centralised services and the climbing reliance on volunteers in the community are economic factors divvying up responsibilities.

Schizophrenia is not a curable disease. Treatments work only to suppress behaviours associated with schizophrenia such as psychosis. Treatment must be ongoing and this maintenance of a medical regime is part of the manifestations of the chronicity of schizophrenia. Since deinstitutionalisation cannot be explained by a cure it has to be associated with other developments. Although advances in psychotropic drugs and changed perceptions of both mental illness and institutional treatment are certainly major influences effecting deinstitutionalisation, budget cutbacks, shifts in palliative care, treatment and the *virage ambulatoire* are also key influences.

The range of influences effecting deinstitutionalisation can in many ways anticipate some of its outcomes. Deinstitutionalisation is also part of the process towards social reintegration. This reintegration provides opportunities and barriers. Integration into our society means finding housing, employment, establishing a social network and living independently while keeping up the medical regime. These expectations of reintegration may be taken for granted by *normals*. They may however, be unfeasible for many schizophrenics whose level of functionality allows them to be deinstitutionalised but does

not adequately allow the demands of reintegration to be fulfilled. In either case, deinstitutionalisation presents the formally institutionalised with options that were unavailable under institutionalisation. Non-compliance is one such option.

Not only does the removal of threatening, forced treatment open up the possibility for non-compliance, but where and how to live and work offer venues for the schizophrenic to be non-compliant with larger social norms. So far as a schizophrenic may embrace deinstitutionalisation but be non-compliant with regards to his treatment or refuse to be socially reintegrated he exercises agency and thwarts the authority of psychiatry. Non-compliance may be a means to dispute the accuracy of the diagnosis. Even so, it is always a means to deny others control over the illness and a confrontation of a socio-cultural system that mandates this control to professionals.

The diagnosis of schizophrenia would seem to leave few venues open to a schizophrenic for the expression of an identity. That identity is restricted by narrowed social networks, few options for employment and housing, threats of sanction and a regimented treatment that while suppressing symptoms inadvertently modifies behaviours. The identity of being schizophrenic also presents options for different sorts of housing, augmented social assistance, different, but vibrant social networks and whole other ways of being – of expressing responsibility, relating to others and challenging social expectations.

Community-based care now means that a range of community services carry the brunt of facilitating this new way of being in the community for schizophrenics. This has allowed for different, non-clinical understandings of schizophrenia to gain acceptance and legitimacy. In addition, it also implies that part of social reintegration as far as it relies on these services, means being mixed with other users of such services who themselves may be extremely marginalised or socially deviant. To be homeless and/or unemployed since (because of) deinstitutionalisation loses meaning when only the fact of homelessness and unemployment are considered. It is in these community-based centres where clinical and

social problems are likely to merge as in the examples of being hard to house and/or a drug user.

Although deinstitutionalisation does not mean wellness, it does imply relative wellness, the ability to be functional enough for release. Deinstitutionalisation itself undermines the concept of chronicity because it is easily mistaken for an indicator of being well. It is difficult to understand what chronicity means in terms of being constantly ill when the efficacy of drug treatments and the symbolism of not being institutionalised indicate wellness. Chronicity as susceptibility to relapse loses out when wellness, in defeating signs of disability, eliminates chronicity as the potential for, or the vestige of, that disability.

Wellness involves following a strict drug regime, making appointments and negotiating the web of social services which has replaced centralised institutionalisation. While on one hand this credits the schizophrenic with being well organised and receptive to the treatment, on the other, there are "rewards" (Goffman's "secondary gains") for being ill such as augmented social benefits. The criminal courts have consistently ruled on insanity pleas that madness removes culpability and responsibility. Institutionalisation and deinstitutionalisation are the expression of a tension and process involving the passing off of responsibility between institution and individual. The stigma of schizophrenia and the stereotype of the schizophrenic move ever closer not only in ideology but also in the individual as compliance and deinstitutionalisation give way to non-compliance and psychosis.

Subjectively experiencing what may or may not actually be a brain dysfunction is only part of the experience of coping with the diagnosis. As much as schizophrenics may have to say about schizophrenia, they have more to say about how our culture invests in biomedicine at the expense of individuality and personality. They have commentaries on the incompatibility of illness and disease where the experience of one clashes with the administration of another. They offer useful discernment of the workings of policy, politics

and how these may best be used with consideration to funding and the goals of society. Once we begin to consider this though we are faced with fundamental questions about ourselves. Never mind psychosis itself, but what is it about its mere potential that is so unfathomable to us that we deny our own otherness? Why do we value our opinions over those of others when these others carry the weight of our opinions and live with the insight? Do we rule by suppression or otherwise force compliance? And what are the consequences of non-compliance?

Schizophrenia as a diagnosis has a long history that reflects and is intertwined with shifts in public policy, changes in attitudes towards the mentally ill, advancement in treatments and the rise and fall of medical paradigms. How the schizophrenic as an individual and clinical entity uses this diagnosis is one point of enquiry into understanding the expectations of the role for schizophrenics in our society and hence the socio-cultural meaning of schizophrenia. Since deinstitutionalisation, schizophrenics have along with increased liberty, been given more options for the exertion of agency and subsequently discovered how such liberties and agencies are circumscribed by societal expectations. Physically navigating the network of community-based centres, manipulating social assistance, confronting expectations for housing and employment and disputing the diagnosis through non-compliance are a few of the new options for this agency. As actions, they are also the expression of what it is not only to live with schizophrenia but also to be schizophrenic.

### **Misgivings**

Clearly this thesis raises a lot of questions and rather than solidly answer any it perhaps simply offers a glimpse into possible ways of exploring those questions. Schizophrenia seems to hold no definitive answer for all people.

This thesis relied on a small sample of an ethnically diverse range of individuals. Because schizophrenia is manifest differently in each person it would be difficult to imagine qualitative research involving a representative sample. Indeed although there were many

things, places and people binding my informants together there were many more keeping them apart. I suppose that even if it is undeniable that these people exist as schizophrenics it can be debated whether or not they represent a group at all or would even constitute one themselves without the defining feature of them being *my informants*.

To understand schizophrenia is to understand psychosis. I cannot deny the delusions and psychosis associated with schizophrenia. Nonetheless, I agree with Dr. Knowles when she wrote:

Delusions have a *phenomenology* rather than raise issues of reality, and schizophrenics (if that indeed is what they are) are productive and useful agents of history who make sense of their own lives and who give useful and original testimony (Knowles, 1997a: 4).

As with all interviews, it is difficult to know what is original testimony and if psychosis wasn't its own stumbling block then perhaps fear of repercussions was. In any case, academically, this thesis posed several problems, particularly as they pertained to writing. Pragmatically, it was often impossible to keep the voice of the narrator and the flow of a particular thought when that flow was interrupted and intersected by several tangents woven into the narration. Ellipses can indicate missing text but not text quoted out of order and in any case the need to edit text heavily undermines the integrity and value of the quotation to begin with. Although the delusions themselves would seem to prevent access to truth, I believe that they simply repositioned truth or retold it from another perspective albeit, sometimes one beyond my abilities to interpret even as metaphor.

Dr. Knowles wrote:

The stories people tell about their lives provide the substance of ordinary biography: and life story narratives (in the sense in which Ricoeur uses his narrative to stake out his hermeneutical project) allow the investigation of lives through the meanings attached to them (Knowles, 1997b: 6).

Although I understand how auto/biography and ethnography are woven together, schizophrenic narratives, fragmented and juxtaposed, potentially leave open not only the meaning, but the attachments as well. Making an effort to give schizophrenics not just *a* voice but *their* voice, it was initially intended that this thesis would come closer to an

autobiographical style truer to a life history. This ultimately proved to be difficult and contributing to my failures were an overwhelming need to interject into the life histories only to invoke my ultimate prerogative as editor and edit, cutting it all short. I should point out that the need for editing was also a result of having others transcribe recorded interviews to text. Quotations invariably needed to be tidied with stutterings, mumblings and distractions ellipsed out.

This thesis then is an attempt that confronts ethnography with a way of story-telling/making that has as much rupture as continuity. Schizophrenia is a conflicted narrative that poses fundamental questions about objectivity and subjectivity especially as that subjectivity is not merely the flip side of objectivity but something made less accessible by the fact of psychosis.

Objectivity, subjectivity and psychosis are not merely what make schizophrenia academically interesting. They are key influences culminating in diagnosis, experience and lifestyle.

It seems for me, unfair to make cross-cultural comparisons with the sample I have taken because most of the informants were from other cultures yet were culturally redefined as Canadian by the system that managed them if not themselves. They illustrate the fallacy of a culturally pure system. More than this however is the continuation of a debate around the validity of a diagnostic category of schizophrenia amid the assertion that its symptomology is present in all cultures. If the category is removed but comparisons between cultures of symptomologies persist then again schizophrenia is submerged into general mental illness and fails to illuminate the particularities of our culture at this time. Besides, it was my intention to show how shifts within our culture (from institutionalisation to deinstitutionalisation) create a particular situation and lifestyle pertinent more to a time in our culture than between cultures. Even if some of the stories presented here and involving migration implicate a schizophrenic diagnosis as a western phenomenon, I am unwilling to have *my informants* carry the cultural weight of their homelands, of Quebec or Canada. I

am also unwilling to offer the peculiarities of Montreal's anglophone community and Quebec's *virage* or system of CLSCs as anything larger than they are. If this thesis is concerned with how our culture is able to define and redefine schizophrenia (and the role of schizophrenics) over time, then as the informants subtly point out, immigration and changes in the "ethnic fabric" of our culture contribute to those definitions.

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