A FRAGILE REVOLUTION

Consumers and psychiatric survivors confront the power of the mental health system.

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ABSTRACT

Despite two centuries and three major reform movements, mental patients have remained on the outside of the mainstream of society, often living in poverty and violence. Today, we are undergoing yet another period of reform and, in an historical first, ex-mental patients, now calling themselves consumers and psychiatric survivors, are being recruited in record numbers by the Ontario government to participate in the change process. Employing qualitative research methods, this study asks four questions: How have ex-mental patients come to re-define themselves as political activists? Second, how have they translated their individual experiences into a collective identity? Third, how do consumers and survivors define their relationship to government given that it tends to speak of them as its partners? And finally, what do they think mental illness is and what should be done about it? The theoretical context of the study is rooted in ideas of social power, concentrating particularly on dominant power relationships. Results demonstrate that survivors are "made" through a process of reaching out for help, expecting empathy, encouragement and guidance, and instead, encountering the violence of involuntary commitment and forced treatment, a betrayal which respondents see as life-transforming. Having come to "know" the world differently, they have turned to the echoing mirror of Other provided by mental health professionals in order to define a politicized identity. To be a consumer or a survivor is to be everything that a professional is not. However, when challenged with the task of developing their own self help and economic development organizations, consumers and survivors found that they reproduced within their own ranks many of the hurtful power dynamics that they so vociferously criticize in the mental health system. The twin pressures of establishing a self help network coupled with responding to an invitation to become the government's new partners have left many feeling worn out. In fact, some have begun to feel that they have been used, pitted against the government's more traditional partners, psychiatrists and unionized mental health workers, as cost control and down-sizing become the main mental health reform agenda under the Conservative government. "We're all afraid," they conclude. Consumers and survivors are afraid of losing what little they have and mental health professionals are afraid of losing their jobs. While it is clear that they have affected the rhetoric of reform, most respondents were unable to celebrate this victory, feeling that words do not equal action. Some respondents say they are dispirited and battle weary. Others say they have finally found a purpose in life. As they struggle to develop their own separate advocacy agenda, they acknowledge that theirs is a fragile revolution but one that is here to stay.

In memory
of

Jack Leader

1918 - 1997

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INTRODUCTION

Historically, no one has particularly cared what mental patients have thought about their treatment at the hands of society. They are, in fact, outsiders, marginalized and excluded from the social, political, economic and medical discourses that struggle with defining the problem of mental illness and by extension, what to do about it. Societies are obviously troubled with the complex and seemingly insoluble problem of mental illness and, over the centuries, have embraced a number of solutions, each of which started out with optimistic good intentions only to deteriorate into the embodiment of the very problems it was supposed to have solved.

In the last decade before the millennium, the Ontario government is attempting yet another reform of the mental health system. This time, policy makers say it will work because we have learned from our past mistakes (Putting People First, 1993). One startling difference between the present period of reform and its predecessors is that the government has actively recruited members of a vociferous group of dissatisfied ex-psychiatric patients to be part of the change process. These ex-patients are part of a wider trend emerging in Canada, the United States and other parts of the world which is loosely being called a " movement." Some members of this movement call themselves consumers. Others take a stronger stand, calling themselves psychiatric survivors because it is their contention that psychiatric treatment is not just unhelpful but "inhumane, hurtful, degrading and judgmental" (Unzicker, 1989, p. 71).

Present mental health reform plans are part of a series of radical changes that are affecting the whole Canadian health care system. Large, centralized institutions and hospitals are "out" and small, local clinics and agencies are "in". Indeed, closer examination reveals that first, from a social perspective, we have come to define health in broader terms; as well-being rather than simply an absence of illness. As a result, a tension has arisen between people's desire to control and enhance their own health and their traditional reliance on medical expertise as the sole source of help and information (Zola, 1990). Second, the perception of serious fiscal pressures reinforced by the recent recession has precipitated a re-examination of the Ontario government's health care expenditures. In doing so, politicians and bureaucrats found that "spending in health care has increased significantly each year [until it has reached] more than 32% of the total provincial budget" (Putting People First, 1993, p. 4). They also found that spending vast amounts of money almost exclusively on illness care, has not improved Ontarians' health (Rachlis & Kushner, 1994). Third, the general politics of health care have been shifting. J. Cohen (1985) states that citizen protest is now openly centred around issues that were once "shielded from public scrutiny by tradition" (p. 701). Birth, death, fertility, AIDS, and all sorts of disease-specific concerns are the basis of a variety of patients rights groups where members openly share stories, pressure local and provincial politicians and march in the streets, if it is deemed necessary, all in the service of their particular health-related cause. In fact, McKnight (1990) believes that the conversion "of a medical problem into a political issue is central to health improvement" (p. 435).

In the present atmosphere of change, the involvement of ex-mental patients along with many other interested groups and individuals in both planning and executing contemporary mental health reform plans sets historical precedent (Simmons, 1990). While a study of this period in mental health history could take a variety of tantalizing avenues, I have chosen to concentrate on what, to me, is its most interesting facet; the political activism of consumers and psychiatric survivors. Thus, it is the aim of the present research to examine the consumer and psychiatric survivor movement on four levels. Using in-depth interviews with 19 of the Ontario movement's more active members, I want to understand first, how ex-mental patients, who bear the burden of intense social stigma, have come to re-define themselves as political activists; consumers and psychiatric survivors rather than "crazies" or "psychos." Second, I want to know how they have translated their personal experiences into political action, both individually and collectively. Third, in light of the movement's substantially increased profile during the present climate of mental health reform, the government has implied that it sees its relationship with this group of people as a partnership but how do consumers and survivors, themselves, characterize their relationship with government? Finally, I ask how consumers and survivors define mental illness and what they think ought to be done about it. In other words, I want to find out what solutions they offer for this complex problem.

Relevance of the research topic

Ex-mental patients have never participated in any appreciable number in the reformation of the mental health system before and have, to date, only had their interests represented by philanthropic others acting on their behalf. Also, this is the first time that they have managed to develop a collective presence where they are seen to be, and see themselves as an identifiable group -- an "us" ready to do battle with "them." As a consequence, studies regarding this group are only now beginning to emerge (Church, 1993, 1996; Duerr, 1996; Wilson, 1996; Emerick, 1995). The present research promises to make its own contribution to what can only become a substantial body of literature examining a new role for ex-mental patients in our society; a role which appears to offer superior rewards in comparison to the marginalized and alienated place we have traditionally accorded this group (Miles, 1981).

Further, mental health reform plans in Ontario are hovering on the brink of implementation. The plan provides the "talk" and goes on to predict that it will take ten years to achieve the "walk." As Eliot warns, "Between the idea and the reality, between the notion and the act, lies the shadow (as quoted in S. Cohen, 1985, p. 93). Given the very serious problems that arose during the last period of deinstitutionalization, it is extremely important that this reform effort be closely monitored. The present plan (Putting People First, 1993) promises a lot, but can it deliver? Research projects such as this one are timely because they offer at least one way of providing in-process feedback on both the plan and its implementation. In fact, many would argue that, given that consumers and psychiatric survivors are the supposed objects of all this activity, their views are among the most important to consider.

Finally, it is hoped that the research will have some applicability in analogous subject areas. For example, the way consumers and psychiatric survivors approach their activism, the issues they face and the solutions they propose have implications for the wider disability movement (Gadacz, 1994). Patient rights groups of all types can observe and possibly learn from consumers' and psychiatric survivors' struggles. Also, the consumer and psychiatric survivor movement is likely to have both commonalties with and differences from other, more mainstream social movements. Understanding one movement can have some value, albeit limited, when examining others.

Expected contributions

Obviously, it is both exciting and fascinating to be researching an historical first, but there are additional reasons why the present study promises a contribution.

First, mental patients and ex-mental patients have been studied extensively for literally centuries and from a variety of perspectives; biomedically (Andreasen, 1984), sociologically (Goffman, 1961; Foucault, 1965), anthropologically (Estroff, 1981) and historically (Rothman, 1970; Scull, 1979). Statistics have been kept, epidemiological rates have been developed and government policies have been monitored (Simmons, 1990). Since deinstitutionalization, researchers have widened their interests to include recidivism rates, community adjustment levels and program evaluation. More recently, ex-mental patients have been studied as members of wider groups such as the disabled (Driedger, 1989; Gadacz, 1994) and the homeless (Goering et al, 1990). Typically, these types of research activities focus on individual deficiencies often called disability, disease, disorder, pathology or deviance. When mental patients are studied in relation to the social whole, it has generally been from the point of view of stigma, alienation or marginalization (Miles, 1981). It is rare for research to focus on ex-mental patients as functioning, active and vital adult members of society with a contribution to make. Thus, one of the expected contributions of the present study will be its emphasis on self-identified ex-mental patients who, despite their difficulties, lead full and useful lives and who, as part of their activism, lecture at universities, speak at legislative hearings, sit on powerful committees, lobby the government, lead rallies, make films, set legal precedent, and on and on; achievements of which most of us only dream. Ex-mental patients, as successful social actors, rather than marginalized deviants, are a new and welcome presence in mental health research, a presence which will no doubt challenge prevailing stereotypes. Additionally, consumer and psychiatric survivor views on how they have transformed themselves are expected to offer fresh insights into the nature of mental illness and health, and mental health policy.

Second, government defines their relationship with consumers and psychiatric survivors as a partnership. However, it is unclear how consumers and psychiatric survivors view their connection to government. The reality is that governmental partners have traditionally been powerful people whose membership in influential groups and associations ensured at least some balance in power relations. Given the vast power differential between government and consumers and psychiatric survivors, it will be useful to examine what views less powerful people have of the government's recent interest in their perceptions and ideas.

Third, what "crazy" people think has typically been of little interest to researchers (Everett & Boydell, 1994), although some newer work has advocated for the clinical value of understanding the patient's experience of his or her of illness (Strauss, 1989). Thus, a primary goal of the present research is to examine consumers' and survivors' own views against the backdrop of the current wave of mental health reform. These new voices offer a fresh perspective on a variety of issues both old and new. They also challenge and confront some firmly held "truths;" some of which have been with us for a very long time.

Finally, the theoretical context of the study, power and power relations, is just beginning to emerge as an acknowledged aid to understanding first, the workings of the mental health system as a whole and second, the interactions of its internal actors in particular (see the Canadian Journal of Community Mental Health, Fall, 1996). The advent of consumer and survivor participation at all levels of planning, developing and delivering mental health services heralds a shift in power that is consistent with present-day global trends as identified by Toffler (1989, 1990). In addition, the theorists (Gil, 1996; Wartenberg, 1990; Janeway, 1980) whose work I have utilized as principal context for the present work are scholars who are interested in power and powerlessness, dominance and subjugation, as wider social constructs and the application of their ideas to the specific case of consumer and survivor activism promises both to enliven and deepen understanding of this group and its new place in the mental health system. Thus, it is hoped that the present work will contribute to the field by reinforcing the utility of power analyses in mental health research.

The research project summarized

In requisite service of defining who I am as researcher and where my interests lie as demanded by qualitative methodology, Chapter 1, begins with a description of my own experience of a psychiatric hospital. As an inpatient psychiatric social worker, I worked with patients who were desperately in need of help and, as staff, I and my colleagues wanted nothing more than to be helpful but somehow we consistently failed. In the closed and tense atmosphere of the psychiatric ward, the primary lesson for us all was that nothing changes and no one gets better. In a search for answers, I turned to the history of insanity to see what it had to teach me about present day mental illness. In Chapter 2, I review the historical patterns of reform which began over two hundred years ago with moral treatment and continue right up to the present with a contemporary emphasis on community mental health and psychiatric rehabilitation. During each period, I searched for patient accounts to juxtapose against the professionally-generated reform discourse in an attempt to discover if the recipients of each wave of change actually felt that they had benefited. As might be expected, written historical records of patient views are sparse but nonetheless consistent -- they did not see themselves as having been helped and, in fact, felt exploited and harmed. Indeed, the benefit of hindsight reveals the inescapable fact that the mental health system has been remarkably resistant to change. For two centuries, intermittent surges of good intentions seem merely to have reproduced the pain and misery they sought to relieve. To me, such resistance was indicative of the need to extend my analysis beyond the narrow confines of historical specifics to the more expansive and revealing terrain of wider social forces. Thus, in Chapter 3, I examine theories of social power. Prevailing critical wisdom argues that the ebb and flow of reform movements within psychiatry, and mental health in general, are simply thinly disguised attempts at designing more and more efficient mechanisms for social control so that society's deviant members -- its outsiders -- can be effectively rounded up and, under the guise of kind and humane treatment, kept from annoying the powerful and disrupting the smooth flow of their privileged lives. Employing theories which define power in terms of a social relationship, I challenge this somewhat narrow view, examining the respective roles of both the powerful and the powerless as they struggle with creating what Janeway (1980) refers to as a *contract* based on dominance. I also discuss emerging notions of power relations such as empowerment and liberation (Wartenberg, 1990) -- both of which appear to manifest themselves repeatedly in reform rhetoric but which, in practical terms, seem only to wither under the omnipresent influence of social dominance.

In Chapter 4, I briefly review the history of Ontario mental health policy which leads up to the present period of reform. Although the results of my research range beyond the borders of the government's official mental health policy as contained in both the Graham Report (1988) and Putting People First (1993), these documents employ powerful words which illuminate contemporary reform rhetoric. They are the present-day version of our society's good intentions. In this chapter, I also examine the complex sets of interests these policies purport to satisfy, noting that families, psychiatrists, unionized hospital workers and mental health professionals in general, have their own agendas for reform, many of which, at least outwardly, seem to collide head on with the views of consumers and survivors.

In Chapter 5, I describe the design and the methodology of the study. Given the theoretical context of the research which concentrates on power, I have chosen qualitative methods as being particularly applicable given their strong awareness of power and power relations within the confines of the research act itself.

Chapters 6 through 10 present the research findings. While the study is cast against the background of a contemporary period of reform, the results extend well beyond the narrow topic of government policy to encompass the fullness of the respondents' lives. In Chapter 6, I offer tentative answers to the first question of the study; by what means have respondents converted their identity from that of mental patient to political activist. Chapter 7 constitutes one of the surprises of the research findings in that it describes the pivotal role that mental health professionals play in the generation of a political identity for consumers and survivors. Mental health professionals appear to offer the study's respondents a necessary mirroring Other (de Beauvoir, 1949) that, in essence, defines much of which they aspire *not* to be. Chapter 8 answers the second question of the study, how have consumers and survivors translated their personal experiences into a collective identity. Respondents' views centre around both the threats and the opportunities created by 3.1 million dollars, dispersed through the government funded Consumer/Survivor Development Initiative. For a struggling, nascent and above all, deeply impoverished movement, this sort of largesse seemed initially like a dream come true but, upon reflective experience, proved itself to have many of the aspects of a nightmare. Chapter 9 looks at the question of what consumers and survivors think of their new-found popularity as the government's partners and finally, Chapter 10 asks what is it that they really want? Results here are centered around the final question of the study, what is mental illness and what is it that consumers and survivors think should be done about it. As a conclusion, Chapter 11 offers a selection of thoughts and tentative understandings that arise from the research findings.

Some caveats

Aside from the standard forms of critiques and debates which this type of research raises (discussions regarding the focus of the research questions, methodological rigor, choice of respondents, data analysis, and so on) there are three inherent limitations that merit remark. First, the work is tied to time. While, upon completion, the study will have taken approximately four years, this time period is brief when compared to the ten years allotted to mental health reform and certainly brief from an historical perspective. It is also research that is focused in Ontario and, to some degree, Toronto, although I make a substantial effort to garner respondents' opinions from other locations in the province. Third, the study is constrained by who I am, as a researcher, and who my respondents are in their roles as consumers and survivors. Thus, the final research product can be said to be a mutually constructed understanding of the topic under study which is, by definition, unique. These time, location and person constraints contextualize the study's findings in such a way as to seriously contain extrapolation. Nevertheless, consumer and survivor opinions and relations, as described and discussed by these actors, here (in this place) and now (in this time), have a contribution to make given the present climate of social, economic and political change.

CHAPTER 1

NOTHING CHANGES AND NO ONE GETS BETTER

In the late 19th century, my great grandfather left Ontario and came West to Manitoba. He was enticed by an offer of free land in return for the back-breaking work of clearing it in preparation for farming. It was a good deal. I grew up on his farm which, by then, had been passed first, to his son and then to his grandson, my father. I also attended the same one-room school where my grandfather and father studied as children.

Prairie farmers, so the legend goes, are tough, independent people who take "nothing from nobody." As with any legend, there is some truth to this one. The men and women in my family prided themselves on making it on their own. Asking for help was a shameful weakness. Of course, what this really meant was that we hid our fragilities and covered our pain. There was a shadow in our background and in typical shadow fashion, its origin was vague and lacking in substance. This much I know. In the late 1940s, something went seriously wrong with my grandfather. Exactly what happened is unclear because the whole business is mixed up with the kinds of things that families don't talk about. Whatever the case, my grandfather, who in his younger years was remembered as a musically talented, charming, but thoroughly eccentric man, became increasingly erratic, angry and, according to one report, violent. When his behaviour could no longer be tolerated, the authorities were called in and they interpreted his actions as the signs of mental illness. In due course, he was sent away to the Brandon Asylum. No one seems to know what happened to him there but soon after he emerged, he died.

Every research project has a beginning and my work on consumer and psychiatric survivor activism has it's roots in my grandfather's experience. A hallmark of conducting qualitative research is the intensely personal nature of the work because, in essence, I am my own research instrument -- both a part of the subject I am studying, as well as the process by which it is studied (Adler & Adler, 1987). Subjectivity -- my consciously constructed view of the social world -- is intimately tied to the eventual research product because, as Rosaldo (1994) states, "the process of knowing involves the whole self." (p. 177). Thus, beginning with what little I know of my grandfather's story, this chapter will offer a personal context for my research by attempting to answer the questions, Where am I coming from? and What's my place in all this?

As with all stories, mine is told in this time, in this place and in this context and were it told in a different time and circumstance, its emphasis and meaning would shift. As Schafer states, "each telling represents one possible version of the action in question" (as quoted in Kohler Riessman, 1993, p. 65). As such, this story is merely a representation of events, combined with what meaning I took from them. Truth, in the narrative sense, is defined as "believability, not certitude, for enlargement of understanding rather than control" (Stivers as quoted in Kohler Riessman, 1993, p. 23).

Becoming a professional helper

In 1984, I entered a psychiatric hospital but unlike my grandfather, I was not admitted as a patient. Instead, I was hired as a staff member, a psychiatric social worker to be precise. My journey from a farm in Manitoba to a psychiatric hospital in Toronto was a circuitous one. When I finished high school in the late 1960s, I followed a rather predictable career path by marrying straight away and having a child two years later. I was twenty-six when my marriage failed. Four years afterward, I found myself thoroughly unhappy with the series of jobs I had had and among the 13.9% of Canadian households that defined themselves as single parent families living below the poverty line (Gunderson & Muszynski, 1990). Up until then, I had been laissez-faire regarding my own welfare but when I speculated on how life was about to unfold for my eight year old son, Matthew, I stiffened my spine and made serious, concrete plans for the future.

I had acquired some university training when first married but with a husband and child on my mind, I hadn't taken my studies seriously. I had been a good scholar once upon a time -- back in that one-room school -- and I thought there was the possibility that I could be again, if I were to work at it. In fact, education was highly prized in my family. My mother had been a teacher (same school) before she married my father and, despite the fact that neither my father nor grandfather had more than a grade school education, I grew up in an atmosphere where reading and self-study was a constant and valued activity. I acquired a reverence for higher learning which was passed on to me through my father's unspoken regret that he had not been able to go further than he had. Thus, when making plans for my son's and my own future, I resurrected the long dormant dream of going back to university and eventually completing graduate school. As is so often the case, once I made a clear decision about what to do, the minor details like finances and where to live, fell into place. I put together an income based on child support payments, student loans and grants. I found a cheap apartment near the university and a suitable school for my son. And I got a job working nights as a waitress in a bar. Three years later, I had enough undergraduate credits to apply for graduate school.

The fact that I became a social worker was in large measure an accident. Getting into graduate school proved a difficult task despite the fact that I had the appropriate grade point average. Working nights and weekends to support myself and my child left me unable to acquire the well-rounded student experience that would have made me a stellar candidate. Anticipating a difficult time finding a graduate program that would accept me, I applied to anything and everything that seemed remotely appropriate. The School of Social Work at the University of Toronto turned out to be the only program that responded to my application and they were sceptical. Before they would rule on the suitability of my candidacy, I was asked in for a special interview so that they could more closely assess my commitment to the profession. Unfortunately, I had only the vaguest of ideas about what a social worker was or what I might be doing if I became one. When I met with the Admissions Officer, our talk went well and I found myself telling her about my dream of attending graduate school and confessing that, in reality, I hadn't really *planned* to become a social worker but, nevertheless, I had worked damned hard to get as far as I had and it was my view that if they accepted me, they wouldn't be disappointed. In the end, I was offered a place in the program. Looking back, it is my hope that I was allowed in because it was understood that having had some life experience was an asset for social work but the alternative reality is that it was an off year for applications and competition was minimal.

Early on in my training, I learned the standard joke regarding my soon-to-be profession. The M. S. W. we were striving for was dubbed the making "Misery Seem Wonderful" degree. We also parodied ourselves by regularly repeating the phrase, "I just want to *help* people!" in a gushingly sincere and thoroughly unctuous manner. Perhaps these types of jokes were meant to dispel our discomfort with the fact that we were about to become professional helpers in a culture that values strength and self-sufficiency above all. Certainly, my roots had taught me that asking for help was a sure sign of weakness. In fact, during a particularly rough period, I had plucked up my courage and asked my family for financial help only to receive a dismissive lecture that began with the pious phrase, "Never a borrower nor a lender be." You made your bed, now lie in it, was the not-so-subtle message. I can still feel the anger and the shame. As a result of that experience, I had at least one qualification for becoming a professional helper. I knew exactly the kind of risk one takes when asking for help.

What is mental illness?

When I graduated from the social work program, it was at a time when finding a job was not especially difficult. Provincial psychiatric hospitals were a known source of entry-level positions and when I applied for an opening, I was hired. Unfortunately, aside from the insubstantial knowledge I held in the back of my head regarding my grandfather's experience, I knew nothing about mental illness or mental patients. Taking stock of my situation, I reasoned that in order to make a success of my new career, I needed to find out first, what mental illness was and second, what I was expected to do about it.

On the subject of mental illness, there were two distinct points of view. My professional colleagues felt that mental illness was a chemical imbalance in the brain, probably as a result of genetic factors -- interesting news given my own family background. It required diagnosis, medication and occasional hospitalization for acute episodes. The Diagnostic and Statistical Manual, the Bible of psychiatry as it is often called, clearly listed the signs and symptoms of mental illness but in its own language; flat affect, dysthymia, ego dystonia, anhedonia -- a veritable forest of opaque terms. However, real life was not arranged so tidily. It seemed that mental illness, as observed in the patients, was a catch-all term that meant a lot of things. Some patients had organic brain damage due to some sort of traumatic accident or disease. Some were called schizophrenic but of that group, some had only had a few psychotic episodes in the past while some were psychotic all the time. Many patients had never been psychotic at all. Some had what was more accurately described as ongoing substance abuse problems. Others had been diagnosed with manic-depression, some with depression alone. A few were developmentally delayed. Some were said to have a variety of personality disorders and others -- well, it wasn't clear what was wrong with them. Nevertheless, all received similar inpatient treatment which involved medication combined with cooking groups, life skills teaching, psychotherapy for a select few -- most patients were deemed unsuitable for "talk-therapy" -- and some off-ward activities like art, music or ceramics.

Discharge from inpatient status required staff to arrange for housing, outpatient treatment, usually in the form of a day program, and financial assistance. As a social worker, my job was to help provide personal history assessments which were documents that essentially told the patient's life story, concentrating particularly on the types of problems that were thought to exacerbate illness, such as marital or familial strife. I was also supposed to help arrange discharge plans. These tasks seemed straight forward. So far, so good.

Things got less clear when I talked with the patients who provided a second and seemingly oppositional view of mental illness. They said that they weren't sure what had gone wrong for them but a psychiatric diagnosis coupled with admission to the local "loony bin," as they called it, had only added to the burdens they already bore; sadness, anger, loneliness, abuse and poverty. Although I was far from naive, nothing prepared me for the extent and nature of their suffering as revealed by their life stories which it was my job to capture. Although there was no such thing as a typical history, most had some combination of the following experiences: sexual, physical or emotional abuse in childhood, gang rape, repeated assaults, separation from family due to abandonment or apprehension by the Children's Aid, assault or sexual abuse while in foster homes, assault or sexual abuse while in youth correctional centres or other institutions, alcohol or drug abuse, a series of violent relationships, interrupted education, sporadic or no work history, repeated admissions to psychiatric facilities, multiple suicide attempts, repeated episodes of slashing, burning or otherwise violating their own bodies, a history of horrendous living conditions in hostels, boarding and rooming houses, periods of living on the streets, physical ailments associated with poor nutrition, and injuries from old assaults or suicide attempts. Patients who were immigrants often came from difficult backgrounds prior to leaving their own countries or, as was increasingly the case, were refugees escaping war-torn nations where they had been tortured and their families killed.

While my own life had not been perfect, it was nevertheless obvious that in the face of this extensive list of disastrous life events, I had clearly had advantages. However, I knew something about sexual abuse. The second shadow in our family, aside from my grandfather's trouble, was my father's revelation in his later years that, for him, our one-room school house had been a place of terror. When he was seven, the School Board hired a young male teacher who did "things" to the boys. My father tended to use seven-year-old words when he talked of what the teacher tried to make him do, how he dreamed that he could get a gun and shoot him, and how the dream always turned into a nightmare because, in his heart, he knew the teacher was even more powerful than a gun. He said that he realized as an adult that it had been silly to believe that if he shot the teacher, he would simply get up and continue to come after him but, he said, "I was just a little guy. I didn't know." There was, however, some underlying truth to my father's nightmare. A teacher, any teacher, was considered a respected pillar of the community. The boys felt, probably quite rightly, that they had nowhere to run and no one to tell -- because who would believe such things could happen? Blessedly, the teacher moved on after one year. Perhaps, he felt that if he stayed longer, someone would eventually tell. But only the boys knew what he had done, or what he would likely do again at his next school. Speaking of these events was extremely difficult for my father and thus I knew that it was also hard, very hard, for the patients to tell their stories.

Knowing my father's experience helped me hear the patients' stories -- whatever their nature -- in a different way. For example, "David" had been admitted to our ward because of a combination of violent outbursts, serious substance abuse problems and suicidal threats. In a talk-therapy session, he related one of many incidents from his childhood. His father was a vicious and violent man who terrorized his family. One day in a drunken rage, he tied his wife to a chair and began pulling out her fingernails with a pair of pliers. David, who was then a small boy, tried to rescue her and was hit over the head with a wine bottle. Bleeding, but not unconscious, he huddled under the kitchen table and listened to his mother's screams as his father continued to torture her.

Hearing these kinds of stories left me with a set of feelings that I had no idea what to do with. I tried to get angry at the cruel, neglectful families that had caused such pain but even that obvious outlet was complicated. While it was easy to assume that most patients never wanted to see their families again, in reality, nothing could have been further from the truth. The role of family in the patients' lives was a complex one. In some cases, it was unclear whether a family was abusive or simply victims of circumstance themselves; of poverty, hunger, illness and early death, violence in unsafe neighbourhoods, untrustworthy friends, inadequate supports to assist with children and so on. In other instances, it was the patient not the family who had become the aggressor, threatening family members or terrorizing them on visits home. In yet other situations, the family chaos was so great that it was impossible to sort out the victims from the victimizers. Even in those families where overt abuse had occurred, there was usually someone, an adult child, a sister, a brother, aunt, uncle, father or mother who had shown concern and offered support.

However, the reality was that few family members visited at all. For those that came, the ward was a daunting place and the staff could occasionally be downright un-welcoming, disliking interruptions in their routine. As it was my job to "deal with" the families, I spent a lot of my time with these visitors. I found them to be confused, distressed, worried and hungry for information. Some spoke no English. Others wanted to help but got tangled up in their emotions, making matters worse. A few, quite frankly, were more disturbed than their relative. Some were tense, angry and blaming. Occasionally, there was a huge upset caused by a family visit that had deteriorated into a fight. But all patients wanted someone -- anyone -- to visit. Many had lost hope because nobody came.

Hearing David's story and the many others like it raised a lot of questions. There was no way I could deny the persistent feeling that if what had happened to him had happened to me, I would have gone stark, staring mad myself. Was this intuitive knowledge the resurrection of some defective gene passed on by my grandfather? Did David also have a gene for mental illness floating around in his DNA that preordained his breakdown regardless of the abuse he had suffered? Seeing as I was reasonably sure that I did not suffer from mental illness, had the gene missed me? And if it had, why was I so sure that if I had had David's experiences, I would have gone crazy, gene or no gene? What actually had gone wrong for my grandfather? David? The other patients? It seemed that I had been spectacularly naive thinking that answering the question, what is mental illness? was simply a matter of asking a few questions, reading some books and getting on with the task of being a professional helper. How could I help someone if neither of us knew exactly what the problem was? Despite these questions, the practical reality of my job was that I was supposed to do something about it -- whatever "it" was.

Help for the patients

The complexity and the severity of the patients' problems were overwhelming and the distress of their families obvious. The staff's views of what was wanted were clear; stabilization on medication, an application to welfare and then discharge to a boarding home with some sort of psychiatric follow-up, if it could be found. When I asked the patients what they wanted, they told me that their problems would be helped if they had someone to talk to. They also wanted the hospital to offer a safe place to weep and to rage about the bad things that had happened to them. Upon discharge, they wanted a home, a job, a family and friends.

These desires were touchingly simple but enormously difficult to obtain. The ward was neither emotionally nor physically safe. A few patients (very few) were unpredictably violent, lashing out at staff or other patients in response to either minimal or no discernible provocation. Even one such patient on the ward left us all on constant alert, never knowing when violence would erupt. The ward rules were numerous and rigid. Their thwarting nature occasioned dozens of verbal and sometimes physical fights between staff and patients, and patients and patients. Emotionally, the ward was in constant upheaval and, while there was a lot of weeping and raging, it seemed to be more harmful than healing. A friendship between patients that began as warm and supportive could swiftly deteriorate into insults. Rivalries would develop that might dissipate, or turn into violent vendettas. Patients, often women but occasionally men, were the targets of unwanted and often clumsily aggressive attention from obsessed suitors. Theft was common. Cigarettes were a valued commodity. Patients who had them traded them for favours while those that didn't spent an enormous amount of time begging for them -- often getting a punch from a co-patient because of their incessant pestering. Some of the more vulnerable and disturbed women traded sex for cigarettes.

For staff, the working conditions were unremittingly tense. The ward was mainly staffed by nurses who were expected to take decisive action when violence occurred. There was no outlet for the feelings they must have had when required to wrestle a violent patient into restraints one day and the next, resume a "therapeutic" relationship. There was no formal acknowledgment that ongoing exposure to the constant threat of violence, punctuated by actual incidents, mattered to either staff or patients. Additionally, the men employed in the hospital -- whatever their professional role -- were informally expected to make themselves available to assist in quelling every violent episode, while the women staff (other than nurses) were expected to respond only if they were unlucky enough to be nearby. Newly hired staff remained "new" until they were assaulted and, after that, they became one of "us." In short, the hospital was hardly a place of healing.

The ward chaos spilled over into discharge plans where a patient and I would work together to sort out the details of getting out of the hospital but many times, our plans ended in disaster. Coordinating the numerous services that were involved in a simple discharge was bad enough, entailing a series of referrals to, followed by appointments with, housing, welfare, a community doctor for prescriptions, a daytime program or activity, and sometimes, a case manager. External programs would often turn patients down and the process would have to begin again. If one component of the discharge plan fell through, it placed other aspects in jeopardy. A complex discharge multiplied problems logarithmically. At these times, we had to negotiate services such as the Children's Aid, probation officers, the court system, lawyers, the Public Trustee, specialized services for physical problems, Meals on Wheels and on and on. In order to work their way through these complexities, the patients had to have a head for details, good interviewing skills, an ability to rise above disappointment when their plans didn't turn out and, last but not least, eternal patience. In the midst of all these demands, the patients would become so anxious they would get into fights on the ward, fall apart in interviews or simply miss appointments preferring to avoid the whole thing.

All of this activity, if successfully negotiated, netted the patients nothing that even remotely resembled the home, the job and the friends they wanted. Instead they left the hospital to take up residence in some of the most dismal, dirty and down-right dangerous housing I had ever seen – boarding homes in the nearby neighbourhood of Parkdale. Also, people were typically referred to day programs, often called day care, which turned out to be a euphemism for a mind-numbing environment where people sat, isolated and alone, day after day smoking cigarettes and drinking coffee. Finally, social assistance, the bulk of which went directly to the boarding home operator, left people living on twenty or thirty dollars a month to cover all their other needs. As a single parent and as a student, I was no stranger to a tight budget but I had never had to make do in such decrepit circumstances and with so little money.

Nothing changes and no one gets better

Psychiatric hospital multi-disciplinary teams, with some variations, consist of a psychiatrist, a head nurse, an occupational therapist, a psychologist, a recreational therapist, a social worker and a number of nursing staff. In the case of the hospital in which I worked, Queen Street Mental Health Centre, team members related to one another in a rigid para-military hierarchy where the psychiatrist's power equalled that of a general. The head nurse, as sergeant, directed the troops (the nursing staff). The other professions, while inferior to the general but better off than the nurses, occupied various ranks as officers.

Our team met twice a week in order to make treatment and discharge decisions. It was extremely rare to have a patient attend these meetings as it seemed to be our job exclusively to decide what was best. The patients' stories, in the form of various assessments including the version for which I was responsible, were usually well known to most of the staff and, although I could see that some were covertly touched or disturbed by the tragedies these stories represented, the team atmosphere dictated that professionalism meant adopting a tough, heard-it-all-before attitude. Nothing, it appeared, could shock or surprise us.

Discussions of what was best for the patients tended to take three routes, but they all seemed to arrive at the same destination; nothing was going to change and no one would get better. The first approach held that the patients were psychotic so much of what they said was simply the impenetrable machinations of a diseased mind and, as such, shouldn't be believed. Those that weren't psychotic were manipulative so they were thought to make up things or exaggerate details in order to get attention. The preferred tactic was to treat the psychotic patients vigorously with medication and ignore or quash the manipulative behaviours of the rest. But, to my eyes, the various medications and dosage levels didn't seem to make much difference and those that weren't psychotic were adept at out-smarting our attempts at behaviour modification, mainly because we could never agree on, let alone carry out, a unified course of action. So, indeed, nothing changed and no one got better.

The second response was that most of the patients' stories were probably true and, in fact, such horrific tales were ubiquitous among patients in provincial institutions who were known to be more "difficult" than elsewhere. Our patients, it was asserted, were the worst in the city and there was no hope of recovery. Treatment consisted of a change of medication, a change of boarding home and discharge, accompanied by the standard admonishment, "You'll be back." And they came back, regularly, because nothing had changed and life hadn't gotten any better.

The third, less common idea but nonetheless occasionally apparent, was the notion that the patients had probably brought most of these things on themselves because they were lazy, immoral and a drain upon the tax-payers' purse. What they needed was a good talking-to in order to instil a proper attitude and a solid work ethic. These talks were considered to be "therapeutic." The problem was that the patients seemed spectacularly ungrateful for the advice they received so they never changed or got better.

Control battles

Power was an important factor in the workings of the multi-disciplinary team. While it is true that most hospitals have a rigid hierarchical structure that assigns power to certain professions, a substantial amount of effort was expended in our team to assure all members that their ideas were just as valuable as anyone else's. This assertion appeared to me to be an illusion because control battles were constant. Given that staff were free to appropriate the patients' stories and interpret them in whatever way we wished, our *ideas* about the stories became the infinitely pliable medium through which we fought among ourselves for control over the definition of the patient's problem and by extension, the best treatment plan. Obviously, it was a given that all patients' problems were fundamentally psychiatric ones, however, within this one restriction there was a wide variety of nuances to the determination of a secondary definition. Would this patient benefit most from help from a social worker? If I could convince the team that such was the case, then I was largely in charge of what happened to the person henceforth. If the problem was more fittingly defined as appropriate for a nursing, psychology, occupational therapy and so on, then I was relegated to a backseat from a treatment perspective and my views counted for less. Clearly, a sense of professional entrepreneurship had gotten mixed up in the decision about the true nature of the patient's problem and the best course of action to take. In addition, as the real authors of the stories -- the patients -- were rarely present in team meetings, they could never contradict a staff member's interpretation of their situation and, as a result, the struggles seemed interminable.

In the end, no matter what perspective prevailed, our discussions were tinged with a deep sense of frustration often directed at the patients who, unaccountably, refused to improve despite the sincere ministrations of the staff. Given the level of pessimism that surrounded the patients' prognoses, it could be assumed that most team members were simply too angry or burnt out to care anymore -- and a few were. But most cared deeply about the patients' welfare and their efforts to help them change and get better were heart-felt and ceaseless. In retrospect, I believe that each of us harboured a different and completely personal definition of what was best for our patients. It was true that our beliefs were related in some way to our professional disciplines with, for example, nurses attending to cleanliness, sleep patterns and regular bowel movements; doctors insisting on medication compliance; psychologists administering personality, IQ and aptitude tests; recreational therapists offering cooking lessons and day trips to local sites; occupational therapists teaching life skills which were intended to lead to some sort of employment; and social workers delving into personal and family backgrounds. However, as I got to know the individual team members better, it seemed that the driving force behind each of our perspectives was more closely related to who we were personally, rather than professionally -- the things that more deeply defined us as *people*; our own upbringing, our relationship with our children, our gender, our race or ethnicity, our politics, and our religion. Whatever the case, team discussions about what was best were intense struggles, although almost always negotiated through a thinly veiled civility where nuances in language and voice inflection were the only signs of conflict.

There was an additional factor, particular to the mental health system, which is helpful in understanding why the patients, themselves, didn't revolt when their views were ignored or misinterpreted by the team. Under the Mental Health Act, our ward psychiatrist could legally hold patients in hospital against their will and, under certain closely defined circumstances, suspend their right to make decisions on their own behalf. The resulting atmosphere was such that all patients, regardless of legal status, were highly unlikely to push to have their concerns heard. The power that these legal avenues imparted to the psychiatrist seemed to create a Sword of Damocles effect where patients knew that, should they protest their treatment plans or anything else too vigorously, bad things might happen to them. The idea that one of these bad things could be the legal suspension of their rights was rarely, if ever, discussed. I don't believe the patients had much of an idea that they had any rights. "Bad," as they defined it, related to the rules and regulations that governed ward activities. Suspension of off-ward privileges, denial of visitors, missing meal times, struggles over pin-money slips, bath and shower times or transfer to another less-desirable ward were much more immediate concerns than vague ideas about rights. They were also the ones over which the staff held almost absolute power.

This is not to say that the patients didn't have their own set of retaliation strategies which they employed to annoy staff members or block, at least temporarily, unpopular decisions. For example, some patients exhibited suspiciously voluntary psychoses with fresh episodes of hearing voices breaking out only when unwanted appointments had been scheduled. Other patients were adept at finding out small, somewhat embarrassing details about staff members which they would announce in a loud voice at ward meetings. One woman drove the night nursing staff crazy by repeatedly tapping on the window of the nursing station. When a nurse would look up to see what the noise was about, the patient would catch her eye, smile wickedly and thumb her nose. As the patient had trouble sleeping, she frequently tapped all night long. A few patients were as talented at psychological interpretation as any psychotherapist I'd seen and when pushed or thwarted, would deliver a thumb-nail sketch of the offending staff member's character that was as razor sharp in its accuracy as it was insulting. Psychiatrists were a favourite target for this type of tongue lashing. In fact, I found that most of the patients were keen observers of the workings of the staff group and at any given time, knew the exact nature of the tensions among the team members, tensions that we seemed to think remained behind closed doors. In the end, however, while these strategies could provoke and, in the case of those patients who lost control and assaulted, actually harm, they remained individual protests rather than organized revolts. In fact, staff tended to interpret these sorts of behaviours as fresh evidence of mental illness although to which disease such symptoms could be assigned was not discussed. However, the bottom line was that the staff were indisputably and irrevocably in charge of the patients' fates.

Who's in charge of the staff?

While patients viewed staff as powerful, the staff, themselves, did not share this perception. To the outside world, it would seem that the staff possessed all the visible signs of power; professional status, respected credentials and secure, well-paying jobs but, inside the hospital, they felt powerless and controlled. The hospital administrators were considered to be the people who carried weight in our lives. From the perspective of the ward staff, management seemed to make decisions which were arbitrary, unpredictable and distant from our daily realities -- much the same complaint the patients had of us. As well, our ability to affect these decisions or to resist them once they were made seemed limited to non-existent. In an atmosphere of impaired communication, the rumour mill functioned full-time but, as a source of reliable information, it fell short of expectation. Thus, in addition to the often chaotic ward atmosphere, staff existed in a climate of ongoing uncertainty, unsure as to what administration might be up to that could have drastic implications for our working lives. In truth, observable change seemed to be an exceedingly slow process, sometimes taking years to implement. But this slowness only added to the anxiety as we were ever on the alert, listening for the other shoe to drop.

Perennial complaints about management were rivalled only by those regarding the amount of paperwork we were required to produce. It was not uncommon for certain regular patients to have clinical charts which, when stacked one upon the other, rose to the height of several feet of reports, assessments, admission documents, discharge summaries and notes of every length and description. However, we all knew that paperwork, while annoying, was not totally purposeless. It left a necessary trail in case something went badly wrong. Something going wrong was the staff's greatest fear and in a psychiatric hospital a lot of things could go wrong. The consequences of making a mistake were little modulated by the size of the error. Nurses could be thoroughly chewed out if a patient for whom they were responsible turned up for an appointment in a dirty shirt. Conversely, a suicide on the ward brought chilling silence. The potential consequences of this mistake -- if indeed it is best called a mistake -- were vast, with the ultimate terror being an inquest where reams of heretofore excessive and unwanted paperwork would be studied under a microscope in an inexorable search for something or someone to blame. Unfortunately, "I'm feeling suicidal" was almost daily conversational currency among the patients. It was a difficult problem deciding when patients had serious intentions and when they were simply using the phrase to communicate bad feelings. In addition, some patients were prone to self mutilation which meant they might slash or burn themselves in a messy and disturbing way but ultimately did not create wounds which were life threatening. Nevertheless, all cues had to be addressed in some fashion or there would be hell to pay.

When patients were deemed to be in imminent danger of harming themselves, they were often tied down in restraints and assigned a nurse to observe them twenty- four hours a day. Some were left ambulatory but were confined to the ward. Others who uttered the threat, perhaps in passing -- who knew? -- and then subsequently disappeared from the hospital grounds were certified in absentia and the police notified. Whatever the case, taking action was costly both emotionally and monetarily with no guarantee that the decision was, in fact, the right one. Had we really averted a suicide? It was impossible to be sure. What was abundantly clear was that any response cost both time and money, and in an atmosphere of perennial funding shortages, it required justification no matter what.

There were many, many other mistakes that one could make; accidentally mixing-up medications, botching some aspect of a discharge plan, averting attention for a few minutes or having a vulnerable patient slip off the ward and end up what? frozen to death in a snow bank, attacked and raped by the more vicious elements of the surrounding neighbourhood, or simply sauntering back an hour or two later with beer on the breath and a satisfied look. Mostly, things turned out well. Patients came back. Correct medications were given. Suicidal threats weren't acted upon. But we never knew. There was always the threat that some incident would end up on TV or the front pages and lead to the involvement of what we viewed to be ultimate power, the Ministry of Health.

The hospital and its workings were small potatoes relative to the entire health care system of Ontario which is administered by the Ministry of Health. Politicians came and politicians went, and so for that matter, did bureaucrats, but no mere personnel change eroded the perceived power of the Ministry. While the staff professed themselves to be powerless in the face of the hospital administration, administration, in their turn, professed themselves to be powerless in the face of the Ministry. As a ward social worker, I don't think I can recall ever seeing an actual Ministry person and this remoteness only added to the mystery. When senior staff attended meetings with bureaucrats, they always said they we going "up" to the Ministry, even though it was actually located across town. In our world, the Ministry equated to the traditional view of God, all-powerful, all-knowing and unpredictably punitive.

Helpless and hopeless

In such an atmosphere, it was impossible for staff to admit feeling inadequate or powerless. These sorts of feelings, although justifiable under the circumstances, were considered to reflect directly on our competency. In addition, we obviously could not learn from our mistakes because we could never reveal that we had made any. It seemed that we were left with almost no honest, self-chosen avenues for growth and professional improvement although, from time to time, management would impose various workshops and seminars. Some were helpful but many were not because we couldn't openly speak about the things we needed to learn.

It didn't take long for me to lose the gloss from my shiny new M.S.W. As far as I could see, the patients had been admitted to hospital with a set of almost insurmountable problems which, they claimed, had been made worse by the ward atmosphere, the lasting stigma associated with an admission to the "loony bin" and the harsh realities that awaited them upon discharge. If all of us, staff and patients, had shared some sort of common language, had been able to hear and talk to one another, we might have been able to agree on what was wrong -- bad as it was. Working together, we might have had a ghost of a chance of improving things. To do so, we all would have had to take mutual responsibility. The patients would have had to examine sincerely which of their own actions and behaviours needed to change so that they could have, at least, a shot at an improved life. We, as staff, would have had to understand what life was really like for the patients and adjust our ward treatments and discharge plans accordingly. Even then, it was manifestly clear that there were many, many things that none of us could fix. No one could give back a childhood stolen by abuse and neglect. We couldn't ensure that people were safe in the boarding homes. It was beyond our power to make psychiatric medication more effective and we couldn't save people from the poverty imposed by a life on social assistance. The benefit of hindsight tells me that we could have *tried* to do some of these things and, perhaps, with a lot of effort and wisdom, had an effect over the long term. In the midst of all this, the clearest and saddest reality was that the patients were desperate for help and we wanted desperately to be helpful. But we couldn't hear one another and even if we had, we seemed doomed to a continual fight over the "true" nature of the problems we needed to tackle. No agreement on what was wrong meant no agreement on what to do about it. As a result, we couldn't begin to make the huge, daunting, but necessary changes that had to occur first, in ourselves, and then in the system as a whole.

All this is not to say that we didn't occasionally have what might be loosely called a success. Sometimes just listening to a patient's pain and rage was deemed helpful. A few took well to the medications and did, indeed, become more stable although that didn't solve their other problems. Others acknowledged that we had, at least, tried. We hadn't made a lot of difference but they were grateful for the obvious effort. Some left and never returned despite the dire predictions that they would do so. I have no idea what happened to them but maybe they went on to better lives. I hope they did. What the patients never seemed to do was to declare this whole thing a useless waste of time and walk out. They, like us, seemed caught in the mutually held delusion that we would accomplish something, sometime.

Moving on

In attempting to answer the questions that introduced this chapter, Where am I coming from? and What's my place in all this? I have offered my version of life in a psychiatric hospital. It must be stressed that these recollections are filtered through a lens that is particular to me and my life experience and, as such, I make no claim on the ultimate "truth." However, they provide one of the backdrops against which the present research can be judged. They also contain a record of many of my biases and blind spots, as well as my vulnerabilities and sensitivities. In that vein, I think it is easy to see that I was thoroughly and completely caught up in the questions this experience raised. While on one hand, I was convinced of the validity of hearing and understanding patient definitions of their own problems, on the other, I was a member of a professional group that often held competing views. Where did reconciliation lie? What is mental illness? What can we do about it? What can formal services do and what can't they do? What is the patient's responsibility in all this?

After almost five years with the hospital, I found that leaving these sorts of questions unspoken, not to mention unanswered, had become intolerable. Also, I too, had begun to believe that nothing would change and no one could get better. In doing so, I was losing my grip on the most essential ingredient in the helping relationship, optimism. I began to search for a way out and, as before, once my mind was made up, the details fell into place. I was offered an opportunity to found a community mental health agency outside the hospital. Over the eight years I have been with this agency, it has slowly evolved into a program that specializes in providing psychotherapy for psychiatric clients who have histories of child abuse. My experiences as an inpatient psychiatric social worker had taught me many things but perhaps the most important lesson was a personal one. Over the years, I developed a growing understanding that my father's own experiences of abuse had affected me in subtle yet highly distressing ways and, as a result, created within me an especially intimate awareness of the havoc that early trauma can produce in both the life of the victim and in the lives of family members. I believe now that I had probably, all along, been seeking a way to put this painful personal knowledge to good use. Thus, I have embraced a specialized professional identity where I have been able to learn the skills necessary to provide the kind of help that my father never allowed himself to seek. And for the first time in my career, I feel that I have found something concrete to offer patients and clients. In fact, I have grown to love my work deeply. While it can be traumatizing, in and of itself, to hear and acknowledge clients' experiences of horrendous childhood abuse, it is also immeasurably rewarding to witness their courage and resilience as they struggle, bit by bit, towards healing and recovery. Things can change and people do get better -- a fact that was originally so astounding that when I first encountered this miracle, I had a deep distrust of it. While it is true that some clients have given up hope and can't engage in the therapeutic process at all, and others -- no matter what the incentive -- will not allow themselves to touch the emotional pain that they carry deep inside, many make substantial, positive changes in their lives. They find and maintain secure housing, develop friendships and are often able to re-unite with a family member or two. One glaring lack, however, has been that most are unable to get a job, any job. An interrupted education, the stigma associated with sometimes years of admissions to psychiatric hospitals and a myriad of disincentives attached to our social welfare system have combined to create substantial barriers to the achievement of employment. Nevertheless, clients who undertake the healing and recovery process, eventually reach a point where they are searching for ways to make a recognized contribution to their community. Given that the traditional avenue of employment is routinely denied, clients have had to wrestle with other solutions – none of which seemed particularly satisfying. In addition, the recovery process usually precipitates engagement in broader social analyses as clients start to make sense, to whatever degree it is possible, of the seemingly senseless and cruel acts they have endured. In doing so, they often adopt a somewhat sociological lens as they analyze first, the family structure which, all too often, can foster child abuse, and second, the wider social forces that spawn and support psychiatric institutions that they feel have re-victimized them or simply ignored the saliency of their life experiences. I have found that this nascent political awakening, when combined with the deep need to re-engage with their social world, has led many former clients towards membership in the consumer and survivor movement. Thus, in my role as therapist, I harbour a distant but kindred connection to the political struggle that they have embarked upon. This connection, when combined with my own experiences of a psychiatric hospital, explains in large measure the subjective motivations that have led me to the present research topic.

The rise of consumer and psychiatric survivor activism seems to have added an especially piquant ingredient to the traditional mix of opinions in the mental health system. While a few of these self-named survivors are my own former clients and some are the same patients I knew from my days at the hospital, they are by no means alone. Hundreds and hundreds of their peers have shifted their identity from mental patient to community activist. How have they accomplished this transformation? How do they get on with one another, make collective decisions, decide on targets for change, take effective action? How do they view the Ministry who now calls them its partners and actively solicits their views? And finally, how do they define mental illness and what do they think should be done about it? These are the questions that form the basis of my research.

In conclusion

I think it is clear that my experiences of a psychiatric hospital left me angry at myself and my colleagues for seemingly making, if not explicit, then certainly implicit promises that we were unable to keep. Had my grandfather encountered the same unfulfilled promises in another time and place? It seemed likely that he had. Provincial psychiatric hospitals have long histories, longer even than my family's hundred year old prairie roots. Therefore, as part of my quest for answers, I have made a study of the history of mental illness -- insanity -- and I have focused my investigations on Queen Street Mental Health Centre, the place where I first began my own professional journey.

CHAPTER 2

FROM INSANITY TO MENTAL ILLNESS TO PSYCHIATRIC DISABILITY

My childhood home was built on land that had been in my family for three generations. When I walked the grounds of Queen Street Mental Health Centre, I was accompanied by over one hundred and forty-five years of history. The asylum, as it had been called long ago, first opened its doors on January 26th, 1850 and the original structure had only been demolished and replaced with modern buildings eight years before I arrived (The Museum of Mental Health Services, 1993). Aided by the hospital's small archival library, I developed an interest in the history of the old buildings and was rewarded by a parallel discourse on the many questions that my present-day experiences had raised. I also searched for evidence that there had been patient, as well as professional opinions on the topic of mental illness.

The question of what credence patients' views should command encapsulated what I now know to have been a Foucauldian concern; the tension between erudite and popular knowledge. Erudite knowledge is composed of scientific and philosophical theories which are formally produced and formally sanctioned. It is most often the result of academic and scientific research and is a major ingredient in what we think of as being "true" about the world. On the other hand, popular knowledge arises from people's everyday experiences and their attempts to make sense of their own lives. It tends to be characterized as naive, common and is "disqualified from the hierarchy of knowledges and sciences" (Foucault in Kelly [ed.], 1994, p. 21). In a reified metaphor, Foucault describes the relationship between erudite and popular knowledge as adversarial, not because they are separate and distinct, but because he believes erudite knowledge to be the systematic re-organization of popular knowledge so that its roots are disguised and its purpose converted to propping up the centralized power of social institutions. Thus, in Foucault's terms, professional theories about the etiology and treatment of mental illness are designed to capture and pervert the true meaning of patients' experiences, producing an ideology which has the covert purpose of keeping them in their place and by extension, mental health professionals in theirs. Indeed, my own observations of the workings of a psychiatric hospital had indicated that there was a difference between patients' and professionals' ideas about mental illness. In addition, staff and patients seemed to have spilt themselves into two separate cultures, each of which was consumed by its own control battles. Patients felt misunderstood and neglected by staff's inability to understand the true nature of their problems while the staff felt disregarded by their management. The whole process was monitored by the looming presence of an ever-vigilent administration and backed by the ultimate power, the Ministry. Walled-up in our separate realities, we seemed unable to access our common goal; the patients needed help and hospital staff wanted very much to be helpful.

This chapter will take an historical perspective, attempting to capture what we, as professionals, have had to say regarding the subject of mental illness versus what they, as patients, have said. I will use the history of my former hospital to illustrate the story of the development of these discourses first, because it is the launching pad for my own career and, as such, maintains a unifying thread throughout the present research and second, because it encapsulates many of the major trends prevalent in Western psychiatric thought (Jones, 1966; Rothman, 1970; Scull 1979; Anthony, Cohen & Farkas, 1990; Carling, 1995). In addition, an historical context for the present study is essential because many consumer and psychiatric survivors, this study's respondents included, have made a project of the recovery of the roots of psychiatry. This knowledge permeates their cultural reality in such a way that it forms one of the necessary background details that gives contextual and atmospheric meaning to both what respondents say and how they say it. Before beginning, however, it is important to note that the history of psychiatry has been told many times. This particular telling of the story is different in that I have concentrated on the ways that professionals have tried to help over the centuries and I have looked for evidence in patient accounts as to whether they actually were helpful. As might be expected, I found that formal academic contributions have been voluminous while patient accounts are rare. Occasionally, the scarcity of a written record of patients' views forced me to employ accounts which were filtered through the eyes of sympathetic professionals and while illuminating, they are not first person stories and, therefore, must be read with this caveat in mind.

Insanity

In 1841, Toronto's population was a mere twenty thousand yet the city had to deal with the same sorts of social problems as its larger and older European counterparts. Insanity was one of those problems. Over the centuries, madness had been attributed to a wide variety of causes; planetary disturbances (hence the term "lunacy"), defects in various body parts, over-exertion of the passions, brain topography, or failed magnetic forces, a theory developed in the late 18th century by Anton Mesmer of hypnosis fame (Doerner, 1981).

However, there was one theory that came to dominate medical practice. It held that disorders in bodily fluids -- blood, phlegm, black and yellow bile -- coupled with hereditary factors were the sources of all illnesses (Baird, undated). Insanity was thought to be caused by an excess of fluid that built pressure inside the body. These pressures were behaviourally expressed as an over-abundance of uncontrolled emotion. Relief was promised through vivisection, cutting a vein and draining up to 40 ounces of blood at a time, or through a less vigorous form of bleeding induced by applying leeches. Cupping involved heating a small, thick-walled glass jar and sealing it to the patient's skin so that a vacuum formed underneath. As the air in the jar cooled, the skin exploded, creating large, weeping sores. Blistering was the application of caustic substances to create the same type of wound. Laxatives purged the bowels and emetics induced vomiting (Tuke, 1885). Usually, these measures were accompanied by a near starvation diet, all in the service of depleting bodily fluids to relieve inflamed passions.

In the case of insanity, a strong sense of moral judgement accompanied medical theories. The ecclesiastical counter-point to the medical view was that people who engaged in bizarre behaviours or suffered from hallucinations were possessed by demons (Hunter & MacAlpine, 1963). Exorcism involved torturing or killing the host's corporal body. Over time, medical theories won out but the notion remained that evil, in the form of vice and immorality, lurked within the insane. The belief was that all humans harboured animalistic tendencies expressed through uncontrolled emotion. Emotions, particularly bad ones such as lust, anger, envy or hate, were considered extremely dangerous and truly civilized human beings learned early to master them (Skulkans, 1979). Over-indulgence produced bad children whose very existence became ongoing public testimony to the inadequacy of the parents' discipline and, by extension, the parents themselves (Parkinson as cited in Hunter & MacAlpine, 1963). By adulthood, however, a person's immorality could escape the privacy of the family home and become a serious public problem. Thus, in addition to vigorous medical treatment, the insane were "re-disciplined" in the most violent manner as society sought to redress the effects of parental neglect (Akernecht, 1968).

These early theories can be recast in today's terms as a nature-nurture debate. Was insanity caused by an inescapable physiological or biological defect of the body, embryonically confined until it expressed itself as a disease? Or was it created in otherwise healthy humans through exposure to a noxious social environment? This either-or tension, biology or environment, is repeated throughout the history of professional discourse on insanity, although it is a mixed-up debate, often with both causalities resting side by side in a single theory without any obvious effort to reconcile their competing influences. It is also the basis for trans-historical themes in treatment modalities which have focused either on curing a disease in the physical body (nature) or on providing a soothing environment and good advice which was intended to persuade the mind to adopt clearer thinking (nurture) (Pilgrim & Rogers, 1993).

In mid 19th century Toronto, the harmless insane were allowed to wander the streets while the city jail, condemned as unfit for human habitation, was converted into a madhouse where the more difficult lunatics were incarcerated.

Its first medical superintendent, Dr. Rees, was considered an eccentric man at the best of times but early on, he received a serious head wound as a result of an altercation with a patient and was thereafter, himself, considered insane (Canniff, 1894). Nevertheless, he remained in charge of the converted jail and followed the medical protocol of the day; cupping, blistering, bleeding, starving and beating. Although these procedures promised relief from insanity, the reality was very different. In 1845, Daniel Tuke visited Dr. Rees's jail and reported what he saw.

> It was one of the most painful and distressing places I ever visited. There were perhaps, 70 patients, upon whose faces misery, starvation, and suffering were indelibly impressed... The foreheads and necks of the patients were nearly all scarred with the marks of former cuppings, or were bandaged from more recent ones... Everyone looked emaciated and wretched. Strongly built men were shrunk to skeletons... every patient had his or her head shaved... I left the place sickened with disgust. (as quoted in Price, 1950, p. 33)

Daniel Tuke was the grandson of William Tuke, a Quaker tea merchant who, upon hearing of the death of a female Friend who had been incarcerated in a British madhouse very much like Dr. Rees's, joined with sympathetic others in order to develop an alternative approach which they called moral treatment. Moral treatment, which favoured the nurture side of the debate, was an attempt to create a utopian world away from the violence and pain of ordinary society. Like many theories regarding the causality of madness, moral treatment held that the patients' families had failed them. And, as before, a cure involved proper re-socialization -- but of a very different sort than the chaining, beating and starving typical of madhouses. Under the tenets of moral treatment, patients were to be housed within the walls of a small country home called an asylum or sanctuary, where order, kindness, beauty, industry, discipline, and devotion to God were to exist in consistent harmony. The asylum's superintendent was to be a benign father figure who lived with the inmates, as did the attendants and their families (Scull, 1979). These homes were to house no more that 100 to 120 inmates, classified and separated into wards according to their gender and the severity of their difficulties, but above all made to feel part of a large, extended family. A sense of family -- a new and improved family -- was considered to be the centre of this restorative community. Patients were also provided with a set of daily chores which, not incidentally, contributed to the running of the asylum. Work was considered absolutely essential because without activity, the patients' minds were thought to atrophy in much the same way unused muscles would. While proponents of moral treatment deplored violence, they did not exclude the use of discipline for patients who failed to follow asylum rules. However, it was only to include such things as withdrawal of privileges and locking patients in their rooms (Scull, 1979).

While not medically based, moral treatment did not negate the existence of a mental disease. The medical theory most compatible with moral treatment was Franz Joseph Gall's science of phrenology (Scull, 1981). Phrenology tied human character and emotion to specific structures in the brain. It solved a thorny problem that had plagued doctors up until then; how to medically treat the mind given Descartes' theory that identified its functions, thought, reason and memory, as essentially metaphysical constructs -- untouchable, unseeable but above all, separate from the physical body. Phrenologists bridged the Cartesian mind - body split by directly relating, in contemporary terms, physiology to psychology. Phrenology stressed that the mind could be gradually modified and improved through the influence of a better environment which, for the insane, was to be provided by the protective atmosphere of an asylum (Cooter in Scull [ed], 1981).

The whole Tuke family took up the cause, along with a dedicated school mistress from Massachusetts called Dorothea Dix (Tiffany, 1891). The Tukes and Miss Dix travelled the Western industrialized world in an attempt to convince local governments to establish asylums in their jurisdictions. Their success was phenomenal. They and their followers can be credited with the establishment of hundreds of asylums housing thousands of people (Hurd, 1917). Foucault (1965) calls this period the "great confinement" where, in concert with the rise of the industrial revolution, all sorts of unwanted people -- the indigent, the criminal, the sick and the insane -- were gathered up and incarcerated with the hope that they could be re-tooled, so to speak, and later released as productive citizens.

Moral treatment became the founding principle for the new Toronto Lunatic Asylum that opened just five years after Daniel Tuke's visit. The architect, John Howard, followed the standard plan recommended by the guru of asylum architecture, Dr. Thomas Kirkbride. In an 1880 essay, Kirkbride described the perfect arrangement in minute detail. The selected site should be several miles from the nearest town, surrounded by fertile farm land and attractive scenery. The asylum, itself, should be contained behind a privacy wall that both kept patients in and curious onlookers out. Within the wall, an attractive and spacious garden was to surround the building itself. Each asylum was to be built with a central, domed and more luxurious administration section signifying the power and position of the father-superintendent and his senior staff. More simply built wings (one for men and one for women) were to project from either side of the administration building to house the "children" of this metaphorical family (Brown, 1980).

Following Kirkbride's plan, the Toronto Asylum was situated three miles west of the city on a fifty acre plot of land known as Garrison's Common which, because of its commanding view of Lake Ontario, had served as a military look-out during the war of 1812 (Brown, 1980). However, by 1850, economy of scale had entered asylum philosophy and the buildings had grown in proportion, from small country homes to huge structures, sometimes housing thousands of patients and staff (Rothman, 1970). The Toronto Asylum was over-crowded from the start with violent inmates mixed in with the more harmless and vulnerable. In addition, its Board of Governors had trouble finding a kind father figure to serve as superintendent. The first candidate, Dr. John Scott, was fired when the affair of "the mangled remains of George Andrews" was exposed (Hector, 1961, p. 9). Dr. Scott, hopeful of a job with the anatomy department of the University of Toronto Medical School, was found to have been surreptitiously dismembering the bodies of dead patients in order to practice the techniques of dissection. He was later to find work as Toronto's coroner. When his successor, Dr. Joseph Workman, arrived at his new post, he faced an out break of cholera. Inspection of the asylum basement revealed that the drains had never been connected to the city sewer system and for three long years, a huge cesspool of excrement had been collecting under the building's floors (The Museum of Mental Health Services, 1993).

Workman appeared to be the first superintendent who could demonstrate some of the attributes of character that a patriarch of moral treatment was supposed to have. In one of his many reports on the operation of the asylum, he stated:

> "recourse to harshness in any form or degree must indicate not merely ill-nature but also utter absence of common sense and correct information. To live among the insane is but to be irresistibly constrained to pity and to love them; and when once this bond is established between the physician and his confiding family, the task of government.. becomes a labour of inconceivable pleasure." (as quoted in Price, 1950, p. 57).

Workman rejected the traditional medical depletion treatments and instead, prescribed "generous diet, well-directed kindness .. and in many cases a judicious allowance of wine and alcoholic beverages" (Price, 1950, p. 56). At the time, alcohol was the preferred method of subduing agitated patients.

During Workman's twenty-two year tenure, he regularly reported to his superiors that the asylum's physical conditions were wholly inadequate, rendering the building cold, damp and smelly. None of the mechanical systems invented to ventilate, cool or heat the huge asylum worked and despite repeated pleas for funds to correct obvious problems, no money was forthcoming. Even more problematic, however, were signs that the promises of moral treatment were unfulfilled. Reports in the local paper alleged that some of the male attendants were allowed to roam the women's wards and that sexual assaults had occurred. In addition, it was reported that a pregnant woman, tied in a straight-jacket, had given birth all alone and unaided (Raibel, 1994). Also, in 1854, William Lyon Mackenzie, leader of the failed 1837 Upper Canada rebellion, sent his daughter to the asylum after his return from exile in the United States. In a series of letters to Workman, he took grave exception to her treatment and described the asylum as a "gloomy, prison-like dungeon" surrounded by unkempt grounds (Raibel, 1994, p. 391). Workman told him to mind his own business. Three years later, while still in the asylum, his daughter died after setting her own clothes on fire.

The reality of confining large numbers of insane people in the huge, underfunded, and impossible to maintain buildings meant that moral treatment, as an ideology, was replaced by the very real concerns of asylum management, or custodial care as it came to be called (Rothman, 1970). Custodial care meant that the sole "treatment" for inmates was the work it took to keep the asylum going. Patients worked the fields, tended the gardens, cooked the meals, did the laundry and scrubbed the rooms and corridors. The idea was that vigorous physical labour promoted mental health and vitality. Patient views took a different form. In 1911, Mary A. a newly discharged Toronto asylum patient wrote demanding that she receive $1248 dollars in pay, calculated at three dollars per week for the seventeen years of her incarceration (Reaume, 1994).

It also appears that the Toronto Asylum had become just as violent as the jail it had replaced. In the 1906 Autobiography of David ----, the former patient reported:

> "This was my worst asylum experience... There were bars on all the windows and no segregation of the patients of any kind. Shocking scenes were a fairly frequent happening. The patients were often noisy and quarrelsome, sometimes fought with the attendants. I saw a young boy of seventeen thrashed with an attendant's belt. They had torn down the clothes of his bed in the morning and accused him of self-abuse and then thrashed him. Near me when I was having dinner a man collapsed and was found to have had a paralytic stroke... no doctor saw him for some time. About a week later at tea one man stabbed another in the neck." (The Museum of Mental Health Services, 1993, p. 14).

Patients also complained that the doctors had no idea what really went on when they weren't on the wards. Clara S. left a letter behind on her chart after a two month stay in 1915:

> "Dr. I am screeming to get ahead of the Nurses as they are bound to cut a patient of their diet everytime they dare to report... I will send you in a correct report of what goes on here among the Nurses. As it is not fair to have everything here reported about the patients. But nothing is said about the Nurses. It is a poor rule that wouldn't work both ways." (Reaume, 1994, p. 403)

Some patients complained of physical symptoms that were clearly neglected or misinterpreted as delusions. In 1910, Annie E. died of a strangulated hernia three months after she wrote the following plea:

> "if I lay down to sleep I cannot stay in bed I am up and down the Hole night. I feel very sorrow to have to explain all this to you but I have been like this longe enough and you Doctors don't pay the slightest atenion to me were you should put the exrase on me and see what is wrong..." (Reaume, 1994, p. 407)

While first person accounts from Toronto Asylum patients are few in number, the themes they raise have been echoed in other work. For example, in a collection of historical writings by women mental patients (Geller & Harris, 1994) Phebe Davis, a woman who spent two years in the New York Lunatic Asylum, says,

> It was not safe for a patient to report one of the attendants to the doctors.. for they would watch their opportunities for revenge on the patients... The physicians would not more than get out of the halls before the help would say, "Now look out ma'am for next bathing day." That meant holding them under water just as long as they dared. (p. 54)

Even if the patients were protected from retaliation, their complains went unheard. Phebe goes on to say,

> I saw a concentration of evils in a condensed form; and when I said anything to the Doctors about the wrongs of the house, they would tell me that it was my insanity. I told them that a fact was no less a fact because it was told by a crazy person. (p. 51)

While moral treatment, as envisioned by the Tukes and their followers, seemed motivated only by good intentions, in practice it rapidly deteriorated into the kinds of abuses that had outraged its original champions. While it is likely that most patients were illiterate or so disturbed that they were unable to report their abuses in any form, the few written accounts that remain are consistent in their condemnation of what had been conceived of as a safe haven. Indeed, like the infamous madhouses before them, asylums, in their turn, became the universal symbol for cruelty and neglect that formed the basis of a second generation of reforms.

Mental illness

When a well-to-do, Yale educated, young man named Clifford Beers (1908) wrote about his experiences in American asylums, people began to take notice. Beers was, in some senses, the first ex-psychiatric patient activist but he worked alone, shunning the company of his fellow ex-patients. With the help of philanthropists, psychiatrists and other professionals, he founded his own reform effort which he called the mental hygiene movement. Proponents of mental hygiene held the perspective that insanity was a preventable brain disease -- a "mental illness," in fact. In Canada, Beers helped form the National Committee for Mental Hygiene with the aid of a number of Toronto doctors and philanthropists (Griffin, 1989). It was a precursor to the present-day Canadian Mental Health Association. The Committee's goals were: to reduce the stigma of mental illness through public education, to see that returning World War I soldiers received proper treatment and that new recruits were screened for psychiatric suitability, to monitor Canada's immigration policies with an eye to preventing the country from becoming a "dumping ground for defectives and degenerates" (Griffin, 1989, p. 30), to provide IQ and psychological tests which assessed the mental health of children, and, finally, to expose conditions in asylums, one of which was the Brandon Asylum in Manitoba in which my grandfather would be confined some thirty years later.

Members of this reform movement argued that asylums had become violent, cruel and neglectful places because there were too few trained psychiatrists and other professionals among the staff (Dain, 1980). Indeed, custodial care, as a treatment technique, had fallen into disrepute. As early as 1878, Sptiza, a young neurologist had mocked that, instead of being medical men, asylum superintendents were experts in gardening, farming and mending roofs -- "in short, expert at everything except the diagnosis, pathology and treatment of insanity" (as quoted in Valenstein, 1986, p. 12). Medical sentiment swung away from social explanations of insanity and embraced a variety of physical therapies designed to treat a bodily disease, now called mental illness. In fact, doctors stated that conditions in asylums were so bad, they were willing to try anything.

> "Padded rooms were in frequent use, incontinence of urine and feces was rife.. some (patients) were extremely violent and tube (forced) feeding was frequent. It was rare for members of staff to walk around

> disturbed wards unaccompanied. (Cunningham Dax as quoted in Simmons, 1990, p. 220)

Some of the more popular physical therapies included pneumotherapy (injecting gas into the spinal fluid); vascular therapy (administering caffeine and other substances to improve circulation in the brain); refrigeration therapy (wrapping patients in artificially cooled blankets and dropping their body temperature as low as 74 degrees F); hydrotherapy (immersing people in baths for long periods of time); histamine therapy (administering anti-allergy drugs); and hibernation therapy (putting patients into a drugged sleep for up to several weeks). Insulin therapy was particularly widespread in the 1940s and 1950s. Comas were induced through insulin overdose and were thought to help people with schizophrenia (Kalinowsky & Hoch, 1961). Doctors also performed lobotomies which involved boring holes in patients' sculls, inserting a long sharp tool and swishing it from side to side in order to disconnect the frontal lobes from the rest of the brain (Simmons, 1990). The inventor of this procedure received the Nobel Prize (Deniker in Ayd & Blackwell [eds], 1970).

Electro-shock therapy, still in use today, was thought to work because of the seizures it produced. Its popularity spread phenomenally and despite broken bones and some deaths that occurred due to the violence of the electrically-induced seizures, patients were shocked as young as three up to 80 or 90 years of age (Kalinowsky & Hock, 1961). In the 1950s, a Montreal psychiatrist, Ewen Cameron, developed a theory whereby he postulated that the cure for mental illness lay in destroying the "pathological behaviour patterns held in the memory storage systems" (Cameron as quoted in Collins, 1988, p. 132). The American CIA funded some of his work because it was expected to provide insight into brain-washing techniques. Cameron combined sleep therapy with intense and repetitive shocks, applied daily for at least a month and often longer (Collins, 1988). The result of such treatment, as experienced by one of Dr. Cameron's patients, was reported many years later in a magazine article,

> "(the treatment) put her into a coma for 86 days.... When she awoke, the young mother of five had been reduced to a helpless drooling infant. She had no idea who she was. She had forgotten how to walk, how to dress, how to use the toilet. She did not recognize her husband, her parents or her children." (Chatelaine, 1991, p. 102)

At the time Dr. Cameron's experiments were being conducted, patients' views regarding life in a mental hospital were not considered relevant. However, it was fashionable to invite esteemed members of the scientific community, regardless of discipline, to give general advice on the patient care and it is through one of these sorts of visits that a unique insight into the lives of some patients was obtained. Frederick Banting, who received the Noble Prize for the discovery of insulin, was asked to visit a number of hospitals and offer his assessment.

> I entered these hospitals assuming the attitude that I was one of the patients... I found that the attitude of the doctors and nurses to the patients was all wrong. They treated the patients as inferiors ... telling them what to do rather than leading them to self help, self respect, and independence. On the other hand, when the patients were by themselves with a minimum of doctor or nurse supervision, they spoke to each other as equals and were really doing a magnificent job therapeutically for one another." (as quoted in Griffin, 1989, p. 82)

Banting concluded that, in order to be helpful, mental hospitals had to radically change their policies and procedures but the mental hygiene movement was in firm pursuit of a medical solution to the problem of mental illness and his advice was not taken.

In the end, Clifford Beers lost momentum. He became preoccupied with trying to prove to his upperclass followers that he was, indeed, sane (Dain, 1980). In the latter years of his life, he spent time in private asylums and passed away before the effects of his movement could be fully assessed. In fact, the mental hygiene movement's involvement in the treatment of returning troops and the screening of soldiers in both world wars helped legitimize the value of psychiatric treatment and expand psychiatry's role beyond the boundaries of the asylum (Grob, 1991). In Ontario, movement members secured funding for the establishment of psychiatric wards in general hospitals and a network of outpatient clinics (Blom & Sussman, 1989). As a result, employment opportunities for psychiatrists and other mental health professionals grew exponentially (Tyhurst et al, 1963). Also, members conducted a number of studies on Japanese and Ukrainian Canadians in search of "the immigrant with a lame or crippled mind" (Reid as quoted in Griffin, 1989, p. 96), an activity that tied some mental hygiene ideas directly to those of the now reviled eugenics movement. However, while it might be argued that the movement offered people a new, and some would say, more respectful language with which to discuss the insane (the mentally ill), the reality was that the public's attitudes remained as negative as ever. Further, the movement's focus on the early detection and treatment of mental illness as a prevention measure had the unintended effect of promoting psychiatric hospitalization among the middle classes who had heretofore largely escaped the psychiatric gaze (Carrol, 1964). And, as a final blow, complaints of abuses within institutions multiplied, indicating that conditions had actually worsened during this particular period of reform (Dain, 1980).

In the welcoming public atmosphere that the mental hygiene movement created for psychiatry, the damaging nature of many of its physical treatments went un-noticed. In fact, continued development of the biological view of mental illness became "inextricably linked to a professional strategy of collective upward mobility" (Pilgrim & Rogers, 1993, p. 105). Eventually, however, theses sorts of treatments gave way to new biochemical technologies allowing big business, in the form of pharmaceutical companies, to enter the mental illness equation for the first time.

The story of the development of psychiatric drugs began modestly in 1938 when Albert Hofmann discovered the hallucinogenic properties of his partly synthetically produced *lysergic acid diethylamide* (LSD) while working for Sandoz (Ayd & Blackwell, 1970). The idea that a manufactured drug could produce hallucinations was of immense interest because, if hallucinations could be chemically induced, perhaps they could also be chemically prevented.

Lithium was originally used in the mid 19th century as a treatment for gout and resurfaced in the 1940s as a dietary salt substitute for cardiac patients, with disastrous results -- patients died from its toxic effects. It was then ignored for many years until a psychiatrist, John Cade, stumbled upon it accidentally. In experiments on guinea pigs, he noticed that the drug produced euphoria and he published his results in 1949. C*hlorpromazine* (CPZ) was discovered in experiments designed to find a suitable drug for hibernation therapy. After administering the drug to a total of thirty-eight patients in a French asylum, Pierre Deniker and Jean Delay published their discovery in 1952. In 1958, *haloperidol* (Haldol) was tried out in the Janssen Laboratories in Belgium and swiftly adopted. Anti-depressants, in the form of *monoamine oxidase inhibitors* entered the market the same year. Enthusiastic researchers tried the drug on seventeen patients with schizophrenia and nine with depression. In the following year, Hoffmann-LaRoche marketed the drug to over 400,000 patients in a product launch which, for its time, was unprecedented in its success (Ayd & Blackwell, 1970).

With these discoveries, it was generally felt that psychiatry was at last on the right path. The rise of both the physical and chemical therapies cast the old Toronto Asylum in a new light. It was no longer considered an asylum where crazy people were kept, but a modern hospital for the treatment of mental illness. In honour of its new role, it was re-named for its address; 999 Queen Street West or simply nine ninety-nine, as it became known locally.

Anti-psychiatric thought and feminist criticism

The new emphasis on psychiatry and the biochemistry of mental illness was offset by an developing field of alternative thought called anti-psychiatry, a collection of views that favoured the nature side of the mental illness debate and tended to advocate for the talk therapies (psychotherapy, psychoanalysis and so on) rather than drugs and shock treatment. Anti-psychiatry, as the name makes obvious, was a strong critique of the profession springing from within its own ranks. In fact, psychiatrists were highly vulnerable to attack because, despite the touted efficacy of drug therapy, the reality was that two hundred years of effort had failed to prove their basic premise; a disordered mind is the result of observable physical or chemical abnormalities in the brain (Jacobs, 1994).

It can be argued that Freud opened the door to criticism. His own theories of psychoanalysis eventually found a welcoming home within psychiatric discourse once he dropped the idea that his women patients had actually experienced incest and began publicly to re-label their stories as fantasies (Herman, 1992). With Freud came the idea that the unconscious, the unseeable mind, could make you mentally ill, and talk, which revealed the hidden pathology, could make you well. At the same time, the plight of returning veterans from both world wars discredited psychiatry's central idea; all mental illness was the product of genetic factors. The trauma of battle had clearly produced the classic symptoms of "disease" in heretofore healthy young men from fine families (Pilgrim & Rogers, 1993) and, as a consequence, the role of environmental factors in the etiology of mental distress took on heightened meaning.

These factors prepared the ground for the first widely recognized challenge to psychiatry. It came from R. D. Laing who published persuasively written case studies of his women patients (1960). His basic thesis was that the delusions associated with schizophrenia were not produced by an illness but instead, had a perfectly intelligible explanation which could be found in the abuse the patient had suffered at the hands of his or her family (Showalter, 1985). Thus, like returning war veterans, patients' "symptoms" were thought to be a set of behaviours that could be traced directly back to real life experiences of trauma. Laing's associate, David Cooper, was the first to call these new ideas "anti-psychiatry" because he argued that the coercive and hypocritical aspects of family life were simply reproduced in the power and trickery exercised by psychiatrists. Laing, an abused child himself, defined schizophrenia as a misunderstood but noble state of being characterized by insight or even prophecy. He argued that people with schizophrenia did not require institutionalization, drugs or shock treatment. Instead, they needed respect and nurturance until their psycho-spiritual crises passed.

In the 1960s, Laing and his colleagues established Kingsley Hall located in East London. Here, they endeavoured to put their ideas into practice by guiding patients through the psychological and spiritual journey that only the outer world called schizophrenia. Kingsley Hall encouraged visits from rock stars, actors and other celebrities but its ability to heal its patients was limited in the chaos of what appeared to be an ongoing party, highlighted by a regular late night event called the lunatics' ball (Showalter, 1985). In the 1970s, burnt out from alcohol and drug abuse, Laing recanted his earlier theories, denying that he had ever thought of himself as anti-psychiatry and even offering a kind word for electric shock treatment. David Cooper further disgraced the group's theories by advocating for what he called "bed therapy." In published papers, he openly admitted to having sex with his women patients in order to supposedly deepen his spiritual connection with them (Showalter, 1985).

However, the anti-psychiatry perspective had other sources of life. In 1961, Goffman published his analysis of life in what he called a "total" institution. In his famous book, Asylums, he stepped metaphorically into the shoes of a mental patient, taking readers through a psychiatric hospital experience as seen through his male, white, middle class eyes. Goffman was a skilled writer and readers were drawn into the life of his fictional patient so that they, too, felt his dawning horror when, abandoned by his family in what at first appears to be a benign and caring hospital, he is inexorably enveloped in the degradation and humiliation of psychiatric treatment. Readers struggle along with the patient to preserve dignity and identity. And, when the patient was defeated, they feel his pain and his loss.

Thomas Scheff (1966) added his voice to early anti-psychiatry perspectives by proposing that mental illness existed chiefly in the eye of the beholder. His studies sought to support labelling theory, a body of thought which held that psychiatric symptoms were not a manifestation of disease but instead, were contextual; appearing and disappearing according to the social milieu in which patients found themselves. Patients' labels -- their diagnoses -- were a short-hand language developed by psychiatrists to identify people who behave differently than the dominant classes. Labels also justified remedial action so that these behaviours could be suppressed through incarceration and so-called treatment. Labelling theorists sought to demonstrate that it was principally the luck of the draw that dictated whether deviant persons came to be called mad or bad. Madness, they said, was simply "a relationship with power at its base" (Burstow, 1992, p. 24).

Thomas Szasz (1974) tackled psychiatric practice from the point of view of its infringement on individual civil rights. He defined the legal powers of psychiatry as "the armed hunt for happiness of the Other" and, as such, the most dangerous of delusions (Szasz, 1989, p. xv). According to Szasz, mental illness does not exist. Instead, it is an elaborate metaphor to justify psychiatry's real role which is to rid society of an extremely difficult class of people. Psychiatry's deception can be seen in the paradox of its powers. On one hand, the profession imprisons supposedly mentally ill persons when there was no evidence that they have committed a crime while on the other, it colludes with the state by finding them not guilty by reason of insanity when it is clear that they have committed a crime. Szasz stated that "if involuntary psychiatric interventions of all sorts along with the insanity defense were abolished, psychiatry as we know it would cease to exist" (p. xi).

The rise of feminism added another perspective to the psychiatry versus anti-psychiatry debate. Women scholars were suspicious of the male-as-all-powerful-therapist theme that ran through anti-psychiatry thinking and they deplored the fact that some proponents openly exploited women patients with impunity. Thus, feminists developed their own distinct analyses that attacked psychiatry through the lens of gender. Chesler (1972) charged that psychiatry had been instrumental in silencing women who did not conform to the standard social roles that had been assigned to them. Using Elizabeth Packard as an example (a woman confined in an asylum in 1860 by her clergyman husband for expressing religious opinions that disagreed with his), Chesler developed the idea that asylums were used as punishment for rebellious women. She argued that the abuses they suffered while incarcerated were simply extensions of those experienced by most women in a patriarchal society. Penfold and Walker (1983) dissected psychiatry from inside the profession. They argued that, because there is no diagnostic test or observable lesion associated with mental illness, diagnoses are merely opinions, but opinions that carry enormous weight. To be *called* crazy by a so-called expert is to *be* crazy. Penfold and Walker believe that psychiatric diagnoses trap women. They describe a situation where, after numerous admissions to a psychiatric hospital, one woman found that "having a psychiatric problem was part of her psychiatric problem" (p. 52). Her husband repeatedly threatened to have her committed whenever he was angry and made certain she understood that he would use her psychiatric record to deny her custody of her children if she tried to divorce him. The authors conclude that the diagnostic language of psychiatry manufactures its own reality which can encircle women, allowing them no exit from the dilemma it has, itself, created.

While anti-psychiatry theorists, feminists and others are highly critical of the psychiatric paradigm and the physical treatments it spawns, the talk therapies for which they so strongly advocate are not, themselves, exclusively benign or non-invasive. Certainly, one very serious problem is the potential for sexual and emotional exploitation. A second concern is the bain of any treatment modality; the talk therapy practitioner may be incompetent, unskilled or, alternatively, employing a theoretical framework which is flawed (Pilgrim & Rogers, 1993). Indeed, from the perspective of the actual patient, psychiatry and anti-psychiatry treatments may not be as far apart as they appear to the protagonists. Each identifies the patient or client as a victim, either of disease or environment. In both instances, rescue is achieved only through professional intervention and finally, each form of treatment can be offered, at least potentially, with dedication and kindness or with cruelty and abuse.

The therapeutic community

The critics of psychiatry were influential in provoking vigorous debate and new ideas. These sorts of arguments created a climate of optimism and excitement at 999 Queen Street West where, in the early 1970s, staff embraced a short lived treatment movement -- at least in the field of psychiatry -- which was called the therapeutic community. It was an idea that re-worked moral treatment's emphasis on the social causes of mental illness and it was championed by Maxwell Jones, a British psychiatrist who was employed in the treatment of World War II soldiers who had broken down in combat. He developed the idea of a therapeutic community which, like moral treatment, sought to provide a restorative environment where patients (he prophetically called them consumers) would learn socially more acceptable behaviours so that they could fit into life outside the hospital. Also, as with moral treatment, the therapeutic community emphasized the social over the biological by seeking to re-organize patients' experiences of their in-hospital stay (Jones, 1996).

Maxwell Jones spent many months in Toronto, influencing administration and teaching the new way (Dukszta, Research interview, 1987). In a therapeutic community, patients were re-conceptualized as active agents in their own treatment. In line with Foucault's ideas about the value of popular knowledge, patients were accorded the right to question the ideas and decisions of professional staff (Jones in Rossi & Filstead [eds], 1973). Open communication between staff and patients was encouraged with the entire group making treatment and ward management decisions together. The hospital environment was to resemble the real world as much as possible so that patients would be able to transfer directly their learning upon discharge. In sum, the primary goal of the therapeutic community was to re-socialize the patients by creating healthy relationships in a "typical" social organization.

While I was still working at the hospital, I took the opportunity of interviewing some of the longer term patients, asking what they thought about the days of the therapeutic community. "Rosie," a frequent inpatient during this time, describes her experience of the therapeutic community this way:

> When you came in, you were assigned to a group. One of the patients who was together -- not someone who was had just gotten admitted and who was out to lunch – would introduce themselves to you and you to them. Now, right away you feel better. You're not surrounded by staff because the paranoia really hits you when that happens. Then they would take you and orient you. This is the cafeteria. This is your room, and so on. And they were your buddy. The patients manned the front desk, taking turns for a couple of hours a day and we never lost a patient. We knew who had privileges and who didn't." (Research interview, 1988)

Rosie also reported that one of the skills she learned as a result of the therapeutic community was the ability to negotiate *quid pro quo* agreements among the patients on front desk duty. For example, she would be allowed to slip out in the evenings and spend an hour or two in the bar across the street without the staff ever knowing, if, when it was her turn for duty, she would extend the same courtesy to her fellows. Thus, the therapeutic community was teaching Rosie a set of skills, probably other than what was intended but, nevertheless, she judged it to be a helpful and benign environment. In fact, after a twenty year association with the hospital, Rosie considered the therapeutic community to be the "good old days" of inpatient treatment.

The staff also remembered it as a particularly invigorating time because the high levels of group involvement in decision-making extended to the administration of the hospital as a whole (Dukszta, Research interview, 1987). While, on the international stage, criticisms of the therapeutic community were heating up, charging mainly that the skills inpatients learned had no particular validity in the real world (Pilgrim & Rogers, 1993), a sudden set of tragic events at 999 Queen Street intervened. In the early 1980s, three patients died due to accidental staff-administered overdoses of medication. Soon, a team of consultants was commissioned to look into conditions at the hospital (Simmons, 1990). The resulting operational review blamed the therapeutic community. The consultants felt that the model, which discouraged locked wards and mechanical restraints, under-emphasized security. Among other things, the report recommended a more scientific approach to patient care, the centralization of administration and management functions, the re-institution of mechanical restraint, and the creation of locked wards (Peat, Marwick & Partners, 1982).

Deinstitutionalization

In concert with the damning report, was the emerging notion that institutions caused more problems than they solved – the exact inverse of the thinking that had created asylums in the first place. The new philosophy, called deinstitutionalization, was summed up by Cohen (1985) as, "small is beautiful, people are not machines, experts don't know everything, bureaucracies are anti-human, institutions are unnatural and bad, the community is natural and good" (p. 35).

In the case of the 125 year old building that was the original Toronto Lunatic Asylum, deinstitutionalization was a literal as well as philosophical threat. The huge structure was showing serious signs of age and, while local historical preservation foundations fought valiantly to save it, it was scheduled for demolition. Even with its new status as a modern hospital and its new name, 999 Queen Street West, the old building's public image was one of fear and ridicule. Nine ninety nine was the funny farm, the loony bin. A local columnist wrote at the time,

> "So they want to save 999. They can't have ever been there. For if you were there once, you would not need to preserve the building. You would never forget it. I can sit here now, surrounded by light and warmth and companionship and recreate that monstrous building, even though it was years since I was there. There are the sounds. The heavy clang of doors shutting some in and some out: the rattle of the keys that in turning brought the outside world in and then closed it off. Those were the sounds of 999. I will never forget them. There were the sights: barbaric reminders of human indignity, human indifference, callousness. But mostly 999 was a smell. If you were never there, I hope you never smell that smell. But if you were, it will never leave your nostrils. Saving 999. Why? I wonder. (Sutton, Toronto Sun, December 17th, 1975 as quoted in Baird, undated)

Efforts to interest the government in preserving the old asylum as an architectural artifact failed and the wreckers ball brought it down. New, smaller, modern buildings were erected on the site and the hospital was, once again, renamed and its address changed in search of a new image. It became Queen Street Mental Health Centre located at 1001 Queen Street West.

It is often said that the true basis for the movement that became known as deinstitutionalization was the discovery of psychiatric medication but the reality was that institutions began to close before medications became readily available (Pilgrim & Rogers, 1993; Simmons, 1990). Other factors such as the rise of the civil rights movement, the overall effect of anti-psychiatry advocates and last, but by no means least, the escalating costs associated with running, renovating or replacing the huge buildings, combined to create a political climate which favoured a mass evacuation of psychiatric institutions. In Canada, two-thirds of its 35,000 psychiatric beds were closed within a sixteen year period (Heseltine, 1983). Unfortunately, the budgets of the remaining institutions consumed as much as the whole system had before (Minkhoff, 1987) partially because of a

300% increase in the number of professionals it employed (Lurie, 1984). In fact, many of the patients weren't deinstitutionalized at all and, instead, were simply transferred to nursing homes or other provincially funded residential facilities (Lurie, 1984). Also, for those who were discharged, the "good" community wasn't as welcoming as had been hoped (White, 1992) and there weren't enough government funded community mental health services to compensate for the diminished role of the institution (Everett, 1994). Many of the newly released patients, facing life in filthy and run-down boarding homes, deteriorated further. Attempts to return them to the institution, coupled with decreasing lengths of stay, created what was called the revolving door syndrome (Minkhoff, 1987). Other ex-patients simply took their chances on the streets.

While each of the three historical periods of mental health reform, asylum, mental hygiene and deinstitutionalization began with the best of intentions, each failed to improve conditions for mental patients who were the supposed objects of all the effort. Each reform movement began life based on a heightened awareness of the horrific ways in which patients were being treated as a result of the "old" order and each, itself, seemed destined only to re-create many of the abuses its was designed to oppose. One of the explanations for this failure has been that there is a pervasive and fundamental flaw inherent in the system as a whole. While psychiatric treatment is predicated on a health care paradigm with the express purpose of curing or ameliorating disease, its primary social utility has been to obtain compliance and conformity by suppressing disruptive behaviour among its patients (Pilgrim & Rogers, 1993). These two agendas, curing disease or controlling unwanted behaviour, places psychiatry and the mental health system as a whole, in the uncomfortable position of having potentially competing masters; the patient who needs relief from suffering and the state who demands relief from the patient's behaviour. Certainly, it is the contention of many critics of psychiatry (Chesler, 1972; Szasz, 1974; Dain, 1980; Ingelby, 1981; Cohen, 1985; Breggin, 1991) that it is the powerful state, which not incidentally funds mental health care, that triumphs in this unequal struggle.

Psychiatric disability

The last professional discourse to be discussed in this chapter is a contemporary one and as such, remains a work-in-progress. In the United States, as a response to deinstitutionalization, the Kennedy administration formally created what was supposed to be a network of community mental health services located outside of hospitals. These services were seen as part of a mental health "system," complementing inpatient treatment with ongoing outpatient support. Over the years, mental illness was thought to have demonstrated itself to be a chronic disorder with many ex-patients supposedly requiring a lifetime of professional services. Thus, instead of holding people for lengthy periods of time in expensive institutions as had historically been the case, they were to be returned to their communities with the goal of embedding them in a comprehensive web of typically small, local mental health agencies. The idea that mental patients require "rehabilitation" for their "psychiatric disability" grew out of Boston University in the early 1970s, championed by William Anthony. Just like people who have suffered a severe physical injury and find themselves confined to a wheelchair, for example, people with psychiatric disabilities are thought to need new skills so that they can live, work and learn in the environment of their choice (Anthony, Cohen & Farkas, 1990). Also, communities, themselves, are supposed to change so that the psychiatrically disabled can be accommodated. Accommodation, in this case, is defined as convincing employers to give the mentally ill a chance, lobbying for funding for subsidized housing and community mental health programs, and attempting to involve or re-involve family and friends in the disabled person's life.

In Ontario, the use of the term psychiatric rehabilitation or as it is sometimes alternatively called, psychosocial rehabilitation, is less pervasive. Instead, being ever practical, we Canadians tend to call community mental health services, "community mental health services." These programs which are typically composed of non-medical services such as supportive housing, case management, drop-in centres, workshops, and crisis services, tend to have developed willy nilly over the past three decades in accordance with the abilities of individuals or communities to promote their ideas to government funders (Boydell, 1996).

Community mental health services are a relatively new development when viewed in the context of this historical review. Nevertheless, a critique has arisen. John McKnight, a long time American community organizer and activist, argues that social services, including the mental health variety, appropriate people's ability to define their own problems and to develop their own solutions. He believes that, just like traditional psychiatry, community services simply find more and more problems to justify their proliferation or as S. Cohen (1985) says, "cast wider, stronger and different nets (p. 38). In McKnight's opinion, community programs have four iatrogenic costs that are rarely, if ever, acknowledged:

> "...the **first** cost is the necessary degradation of the individual's self-concept by the messages of deficiency, wrongness, brokeness, and need that the helper brings.... the **second** great iatrogenic effect is that we have decided so often for the service intervention that we have now taken the majority of all public investment in the poor and given it to non-poor people, who are called "servicers." The **third** effect has to do with the fact that each time we say ...we need more services.. we are always diminishing the community's powers by investing in the system's powers. The **fourth** negative effect (is)... when you get enough services intervening in a person's life, you will create a forest of services. So aggregating services around people creates new environments that will (paradoxically) guarantee deviant behaviour." (McKnight, 1994, p. 5 - bold added).

Families are an additional source of dissatisfaction with community mental health services, and the mental health system as a whole. They argue that their relatives are victims of the revolving door syndrome and that community services allow people to "fall between the cracks" (Boydell, 1996, p. 20). They also point out that mental health professionals, on one hand, blame them for creating their relative's mental illness while on the other hand, hail them as the solution to the problem of rising costs in the health care system. Indeed, family members have become, defacto, the major source of unpaid caregiving in the deinstitutionalized mental health system. Seventy-two percent of discharges from psychiatric facilities send patients directly to their family residence (Marcus as cited in Boydell, 1996).

In conclusion

Over the last two hundred years, professional discourse has swung to and fro between biological and social explanations of mental illness and has seemed incapable of moving beyond these two, often polarized viewpoints. Each new wave of opinion promised help and a better way of life while patient accounts, which are admittedly limited in number, primarily exposed cruelty, violence, humiliation and neglect.

Unlike other eras, the present period of mental health reform in Ontario, along with ideas about psychiatric disability and community mental health services, has arisen at a time when ex-patients, now calling themselves consumers and psychiatric survivors, have entered the picture in substantial numbers for the first time. While their forebears tended to confine themselves to pleading for better and fairer treatment at the hands of their keepers, this new breed of activist seems to be taking a different approach. They are often well versed in the history of psychiatry and almost always knowledgeable about current professional discourse. They have also served notice that they are possessed of what Foucault (1994) calls popular knowledge and through the telling and re-telling of their own experiences at the hands of the mental health system, they intend this time to hold professionals accountable for their actions. Things are changing. And, in the light of these changes, the goal of the present research is to find out who these new activists are and ask what is it that they want.

CHAPTER 3

POWER AND PROTEST

Many years after the completion of his famous text, Madness and Civilization, Foucault (1977) decided that the history of psychiatry is, in fact, a genealogy of power but, as he said, "I am perfectly aware that I scarcely ever used the word or had such a field of analysis at my disposal" (p. 115). My own experiences as a staff member in a contemporary psychiatric hospital bear personal witness to an ongoing struggle among a set of power relationships in which the patients, staff, administrators and the Ministry were embedded. It appeared that everyone felt powerless in relation to some more powerful entity and, while the patients clearly needed help and the staff wanted to be helpful, not much seemed to work. The preceding historical review identifies these types of relationships as reproductions of wider social struggles. Each period of reform overtly or covertly located the source of the struggle in the family. Eventually, through the ambassador of an un-regulated and "defective" adult child, private familial struggles spilled into the public sphere where they became the state's problem. The task of psychiatry was to extinguish the offending behaviours but, instead, it seemed only to re-create and, in many cases, magnify the original damaging atmosphere.

Foucault (1994) argues that it is not enough to identify the existence of a struggle and just leave it at that. Instead, it is necessary to ask what are we struggling over? Who is involved? How, where, by what means, and according to what rationale has the struggle evolved? The benefit of hindsight makes it possible to offer some answers to these questions. In the case of mental illness, the people who have historically been most involved in the debate have tended to be society's elite; the well-educated, those holding professional status, sometimes wealthy philanthropists, often politicians or government officials. These are powerful people and it is their ideas that have shaped our notion of what mental illness is and what to do about it. The battle ground has been the drawing rooms of the wealthy, the academic classroom, medical journals and government legislatures. What have we been struggling over? Foucault (in Kelly [ed], 1994) states that "we are subjected to the production of truth through power and we cannot exercise power except through the production of truth" (p. 31). In our society, the "truth" is often purveyed to us through the medium of erudite knowledge; in this instance, formally produced and sanctioned theories about how mental illness is caused and how it might be cured. The stated rationale for the production of these theories has been the desire on the part of the elite strata of society to be helpful to those who are suffering. However, Foucault (1965, 1977) and many others (Szasz, 1974; Ingelby, 1981; Dain, 1980; Cohen, 1985; Breggin, 1991) argue that "helping" is merely a thinly disguised justification for locking troublesome people away so they don't annoy us. Dain (1980) insists that each era of reform amounted simply to a series of improved methods for social control, principally because those directing the changes were from the same social classes and groups as those perpetrating (or ignoring) the abuses. In fact, the medical and psychiatric enterprise has often been likened to a self-sustaining industry that, at one and the same time, produces illness and then, offers to treat or cure it (Albrecht, 1992; Gadacz, 1994).

Whatever the ascribed motivation, the erudite discourse that has evolved around mental illness has been an ebb and flow of explanations that alternately emphasize physical disease or social causalities -- nature versus nurture. Anti-psychiatry proponents and feminists have re-cast the debate in contemporary terms and have added a dimension to our understanding but the alternative treatments they propose have also demonstrated a potential for abuse and exploitation. Within the confines of Foucault's ideas regarding erudite and popular knowledge, the apparent reason that the debate has proven itself to be repetitive and circular is because it is the same classes of people who are continually arguing point and counter-point.

While the rhetoric of how to cure or ameliorate insanity, mental illness or psychiatric disability has been a hotly contested area of struggle, no one except the patients seems to have been terribly concerned about the outcomes of the various theories and approaches (Cohen, 1985). Decade after decade of supposedly good intentions has not produced the hoped-for results and, in many instances, has fostered cruelty, violence, exploitation, humiliation and harm. Thus, a conspicuously missing ingredient in this ongoing debate is popular knowledge -- the everyday experiences of the objects of the struggle -- patients and ex-patients. While, historically, a few lone-wolf advocates have risen to prominence, Clifford Beers being a notable example, he and others like him, as individuals, don't seem to have been able to make much headway. Now, substantial numbers of people calling themselves consumers and psychiatric survivors have entered the fray. In doing so, they are attempting to breach the perimeter of a tightly knit circle that has a long history of exclusive membership. The addition of a new set of actors in the traditional struggle over the "truth" about mental illness highlights power and power relations in a new and bold way.

Capitalizing on the benefit of Foucault's hindsight, this chapter will offer a field of analysis that includes ideas and theories about how power operates in our society with the goal of rendering visible that which often disguises itself as natural, inevitable and impersonal (Miles, 1985) -- as just the way things are. Power is a complex subject and I have chosen, as my principle navigational aids for the analysis and presentation of the research results, a number of texts including Elizabeth Janeway's 1980 feminist work entitled Power of the Weak because it discusses both sides of the power equation -- the powerful and the powerless -- and because it elucidates the oft-neglected relationship between the two. Other ideas and theories are included first, to discuss the wider social power structures in which the mental health system is embedded (Gil, 1996), second, to tie the various theories specifically to the field of mental illness (Miller, 1981, 1984) and finally, to move the discussion beyond the typical but narrow definition of power as dominance (Wartenberg, 1990).

Power as dominance

Mental illness is a particularly difficult problem for society to deal with because it evokes a duality of feelings within us. On one hand, citizens pity the mentally ill and feel an obligation to care for them. On the other, they are afraid of them and feel in need of protection. Leifer (1990) concludes that "the main social function of public psychiatry is to provide a mechanism for covert, extra-legal social control without violating the principle of Rule of Law" (p. 249). This idea is intuitively attractive because power is often thought of in uni-dimensional terms -- as limiting and constraining, even as an evil force that can harm us or make us do things we'd rather not. From this perspective, psychiatric power would be defined solely as *dominance*.

In his work on the theory of power, Wartenberg (1990) provides a kind of developmental history of dominance. He argues that a contest for power is, in its most basic form, a violent life-or-death struggle. One combatant proves stronger than the other and the loser dies. However, with the conquest comes the loss of the object of subjugation and, in a sense, both combatants lose although obviously not equally. Hegel's famous essay exploring the power relationship between master and slave demonstrates that in certain relationships, there is no need to prove who is the stronger because it is a foregone conclusion acknowledged by both parties. However, death remains an ever-present possibility that secures the slave's obedience. Neither the master nor the slave want to precipitate a life-or-death struggle as the slave would lose his life and the master would lose his slave, along with the profit the slave would have produced. Hence, they remain locked in a relationship of domination and subjugation which doesn't need an ongoing show of force to maintain it, but, nevertheless, requires a certain level of coercion.

The possibility of resistance is heightened where coercion exists. Revolts and rebellions often occur and, as a consequence, Wartenberg believes that a natural progression in the process of domination is to develop "misunderstandings among the dominated about what is happening to them" (p. 127). These misunderstandings become an ideology that rationalizes dominance, even in the eyes of the subjugated. Some examples of these ideologies are arguments that try to demonstrate that everyone benefits if one group is in charge. Other ideas maintain that it's biologically pre-ordained for one group rather than another to be in a superior position. In this way, those who are dominant conceal the fact of their domination and lessen the possibility of costly incidents of resistance, achieving what is called hegemonic control. The unique aspect of hegemony is that it is largely invisible. As a result, members of both dominant and subordinate groups alike are less likely to question the control mechanisms that maintain the relationship.

Wartenberg extends these ideas further with Nietzsche's theories of valuation. A valuation is a judgment that acquires the guise of "objective truth" (p. 133). It rules on the rightness or wrongness of certain behaviours and functions to persuade people not to do what they might otherwise do or, conversely, to do what they otherwise might not. Nietzsche's ideas point out that neither force nor coercion are essential to the maintenance of domination. It "can be constituted in the realm of belief alone" (p. 134). When ideas become the tool by which domination is achieved, Foucault believes that the mastery attained is no longer associated with a threat of death but with a "taking charge of life" (as quoted in Wartenberg, 1994, p. 138). Honneth refers to this process as the colonization of the life-world and describes it as "the denial of meaning, feeling, identity, individual autonomy and the appropriation and commodification of the behavioral structures of individuals" (as quoted in Gadacz, 1994, p. 111). However, ideas of domination may have little power in and of themselves without the endorsement of a higher authority. For example, the church has ruled over the powerful and the powerless alike by invoking the word of God. And, as the history of psychiatry points out, the power of God can be replaced by the authority of science.

Gil (1996) argues the mechanisms of dominance create a society that is structurally violent. Historically, we have evolved meta social power relationships where it is viewed as "natural" for a few to have a lot and many to have little. Examples of such power relationships are monarchies, feudalism, fascism, dictatorships, and our present system of capitalism. However, all humans have basic needs that must be met for healthy and peaceful societies to exist. Citing Maslow, he states that, first and foremost, we need to have our biological and material needs met. We must be clothed, fed and sheltered. Second, we are social beings and we require the company of our fellows. We need family, friends and community. Third, we have productive, creative needs which, in our society, are most often expressed as work. Fourth, we need at least a minimum level of security and safety. We want to live lives that are free of violence, crime and war. And finally, we want to grow and improve so that our life journey is one of evolution and positive change. Finally, we seek spiritually-based meanings in our existence. We need to know that we have a place in some larger order, even if we are unclear as to its true nature or purpose.

In a society where power relations are based on dominance, a few are able to meet most of their needs while many may not be able to obtain even the basics of life. The result is a division where one relatively narrowly defined group occupies space within society's universe of obligation while many, many others remain outside (Gamson, 1995). Gil (1996) calls this circumstance initiating social violence although it has many other names; subjugation, oppression, racism, sexism, homophobia, colonization and marginalization. The resulting latent energy created by oppression can foster instances of reactive counter-violence (rebellions, uprising, revolts and strikes) which, in their turn, are met with the meta forces of a sanctioned and often legislated socially repressive violent response. The interactive spiral of initiating social violence, reactive counter-violence and sanctioned retaliation are the components of the structurally violent society in which the mental health system is embedded.

From Wartenberg's (1990) perspective, the power of those who rest inside the universe of obligation depends on a type of social shell that surrounds them. This shell is constructed from valuations backed by higher authority, sometimes called legitimizing symbols. In the specific case of psychiatrists and other mental health professionals, an important legitimizing symbol is the acquisition of one or more formal university degrees but it is also highly likely that they "wear" other social cues of status such as being white, being Canadian-born, being male, being straight, being middle or upper class or being wealthy. The more high status cues, the more prestigious and unassailable the social shell and the more secure the membership within the universe of obligation. Should anyone have the temerity to question the wearer's authority, protest can be quelled through an invocation of ideas of valuation; rational scientific 'truths,' which are produced and maintained by the professionals, themselves, and backed up by what S. Cohen (1985) calls the higher authority of "doing good" (p. 114).

Viewed from the angle of dominance, psychiatry can indeed be construed as a power relationship that results in social control. Legitimized by the acquisition of professional credentials, backed by the power of scientific authority and supported by an ideology of doing good, psychiatrists, as members of the universe of obligation, have been accorded the power under current Rule of Law to hold their patients in a psychiatric hospital against their will for a specified period of time. Also, in specific cases, they can force medications, seclusion, mechanical restraint or electro-convulsive therapy (ECT) upon them. The focus of these sorts of dominant power relationships is control of the other. The goal is compliance. The tactics used escalate from persuasion to force and coercion. In service of hegemonic control, such measures are called "help" and are seen as for the patient's "own good." Thus, from Gil's (1996) viewpoint, psychiatry's role is the maintenance of one of society's legally sanctioned repressive responses.

For your own good

Defining power solely as dominance is best described as "something we come by honestly," meaning that we are taught it very early in life. Alice Miller, in a series of influential books (1981, 1983, 1984), examined the nature of our culture's child-rearing practices. She developed her ideas after she retired from a twenty year career as a psychoanalyst. She had become increasingly uncomfortable with many of Freud's child development theories which she felt did not fit with the everyday experiences of her patients. Also, as a German citizen, she felt a personal need to find an explanation for why a man such as Hitler had existed, and why he had so thoroughly mobilized the darkest impulses of the German people. At the completion of this latter quest, she concluded that Hitler's upbringing had not been unique and that, in fact, hundreds of thousands of people had been raised as he had been, in hatred and violence where the only choice was to harm or be harmed. At first, it seemed that what she had discovered was an extraordinarily high prevalence of severe child abuse in pre-war Germany. However, she concluded that the standard practices of what society calls good parents -- people who are trying hard to do the right thing -- were, and continue to be, deeply flawed. She charges that our Western child-rearing techniques are inherently hurtful, coercive, humiliating and often violent -- the same criticisms that are often leveled at psychiatric treatment. Some of her work (1984) pairs historical and contemporary advice-to-parents books with heart-rending vignettes of how small children must feel when subjected to these time-honored punishment practices (love withdrawal, spanking, threats, shaming, humiliation, teasing, isolation, and with-holding favourite objects). She hypothesizes that children, who are wholly dependent on adults for everything in their little lives, experience parental power as dangerous, absolute, unassailable and cruelly thwarting of their needs. In the face of the all-powerful adult, children see themselves as completely powerless, unable to communicate their needs effectively or express the sense of injustice they feel if they are harmed or ignored. Expressions of rage lead only to retaliation until the child learns to be "good," which in fact means fearing his or her own emotions and realities, and accepting only the parental view of reality as the "truth." In Gil's (1996) terms, the child is experiencing the spiral of structural violence.

Miller points out that, while some parents are overtly abusive, most are not intentionally cruel people. They, like everyone else, were raised in exactly the same fashion, internalizing their own experiences of dominance and mistreatment, denying their feelings of rage and despair, and repeating the same injustices with their own children, employing the oft repeated phrase, "it's for your own good." Churches and schools, as part of our culture, also use public humiliation, shaming, threats, and, until quite recently, corporal punishment to control their small charges.

Thus, our first experiences of power teach a "poisonous pedagogy" which reads as follows:

> 1. Adults are the masters (not the servants!) of the dependent child.
> 2. They determine in godlike fashion what is right and what is wrong.
> 3. The child is held responsible for their anger.
> 4. The parents must always be shielded.
> 5. The child's life affirming feelings pose a threat to the autocratic adult.
> 6. The child's "will" must be broken as soon as possible.
> 7. All this must happen at a very early age so the child "won't notice" and will therefore not be able to expose the adults. (Miller, 1984, p. 59).

One aspect of the damage created by this pedagogy lies in the incongruence between what the parent says versus what is done. In order to teach children societal values such as it's wrong to lie or to hurt others, parents, in fact, "resort to lying, deception, cruelty, mistreatment and to subjecting the child to humiliation" (Miller, 1984, p. 64). Children do not miss the hypocrisy inherent in "do as I say not as I do" and acquire a double sense of unconscious injury when they are disciplined for imitating their parents' behaviours. They also come to understand that openly identifying inconsistencies in the parental regime is a dangerous thing to do. In sum, they are suspicious of power and powerful people, afraid of their own powerlessness, as it manifests itself within their own interiors -- and, understandably, loath to question those in authority.

Among the contributions Miller makes is first, to sensitize us to the emotional life of the very small child and connect it to the adult that the child inevitably becomes. While, on the one hand, we seem to be able to understand that small bones are physically fragile and may shatter with one blow, on the other, we appear to be completely neglectful of the child's highly vulnerable emotional development. She also alerts us to the possibility that many of the discipline techniques that our culture sanctions in order to produce law-abiding citizens actually harm children and harm them in specific ways. They grow up with a parentally-induced fear of their own emotions combined with very little confidence in their perceptions of reality. In short, they know exactly how bad it feels to be powerless but they have had no opportunity to develop a sense of their own power. As a result, they inevitably come to misuse that which they don't even know they have. The psychodynamic explanation for this misuse is called splitting off and projection (Miller, 1984). Essentially, children split off and repress that aspect of themselves that they have learned to hate because it has led to so much pain -- their feelings of vulnerability and powerlessness. Given that they have no way to communicate their self-hatred, children, as they grow into adults, act out their feelings by projecting their hatred of their own vulnerability onto others. Obviously, their own children are prime targets for this projection. As a consequence, parents may not protect their powerless child as they should, but instead, attack and belittle this "failure" with special venom. Also, society as a whole, may retain deeply ambivalent feelings towards its more vulnerable citizens and feel very little obligation to examine the outcomes of its so-called good intentions. We have learned that it's what we say that is important, not what we do.

It appears, then, that the incubator for our culture's citizens -- the family -- prepares its children for adult social life by recapitulating Wartenberg's processes of domination. In a constant replay of the life and death struggle, babies enter the world as a completely powerless and dependent beings that will surely die if not cared for by all-powerful adults. Janeway (1980) adds that the most crippling events for children are "repeated experiences of vulnerability and helplessness" (p. 52). As children grow older, culturally sanctioned discipline techniques create systematic "mis-understandings" that tell them that, no matter how they feel about it, what their parents do is "for their own good." Protest merely pits the powerless child against that which is unassailable -- the revered institution of the family whose power is backed by both the state and God. As children reach adulthood, they retain both their deep feelings of powerlessness and their mistrust of power and powerful people. They also may harbor an unconscious hatred of their own former vulnerability which they project onto individuals or groups who are visibly fragile. Then, they become parents, and the process begins anew.

These discussions of parental dominance illuminate two aspects of power as demonstrated by the history of psychiatry and my own experiences of the workings of a psychiatric hospital. First, both the powerful -- the elite and professional classes -- and the powerless -- mental patients -- have learned about power from the same position, that of helpless children. As Janeway states: "*All* of us have experienced, one way or another, what it feels like to be vulnerable and helpless, and we can't unlive those moments" (p. 93). Thus, combining Alice Miller's view of parent-child interactions with Gil's (1996) concepts of initiating social violence provides an understanding of how the following two claims can both be true: First, psychiatrists, mental health professionals, administrators, bureaucrats and politicians are members of our culture's dominant class. Second, they do not experience themselves as dominators. As a result of this paradox, professional discourse on mental illness is rife with what Janeway (1980), as a feminist, would call paternalism but which might be more properly termed *parentalism* -- "a model which includes not only control over, but also affectionate regard for (its) subjects" (p. 95). The essence of parentalistic help is to offer charity and kindness on a case-by-case basis while, at the same time, reserving the right to withdraw aid or resort to abuse and cruelty if some sort of transgression arises. Transgressions can spring from three sources. First, the recipients of the help may not display sufficient levels of gratitude. Second, they may fail to demonstrate benefit from the help they have received. They may not get well, do better or change. But the most frightening threat of all to the parentalistic impulse is the potential for reactive counter-violence. A whole crowd of powerless and needy people, because of their number, cease to be viewed as worthy individuals and, instead, become defined as a grasping rabble who invoke buried memories of powerlessness and vulnerability in the dominant classes. From that point onward, it is no great leap to re-define specific vulnerable groups as a dangerous "they" who are in need of a sanctioned repressive and often violent response which is called "help" and justified as being "for their own good." Thus, people who are situated in dominant positions but who do not experience themselves as powerful, can quite easily define both kindness and abuse as for the "best." They can also back up either impulse with scientific truths and feel little incentive to examine the dissonance between the rhetoric of helping and their own actions. In other words, the fact that good intentions might not produce positive outcomes is overlooked.

Disorders of power

A persistent theme throughout the history of psychiatry has been the view that family life has something to do with the genesis of mental illness and despite the rise of the medical model and biological psychiatry, this idea simply has not gone away. Alice Miller argues that our culturally based parent-child relationships create "normal" children who grow into adults with suppressed emotional lives, little understanding of their own power and a lack of confidence in their own perceptions of reality. Miller adds that, in the extreme instances of overt child abuse, a far more common experience than heretofore believed (Bryer et al, 1987; Ogata et al, 1990; Firsten, 1991; Goodman, Dutton & Harris, 1995; Lipschitz et al, 1996), there exists a clear prescription for the creation of many, many problems in the adult child, with mental illness being only one of the possibilities. Janeway (1980) re-names these problems as "disorders of power" (p. 51) while Gil (1996) would tend to think of them as individual examples of reactive counter-violence. Janeway defines their source in the following manner:

> "No matter how bizarre the behaviour of an individual child, the symptoms stem from common responses to common dangers within the human situation, responses that appear when power relationships tip out of balance" (p. 50)

Disorders of power are crippling and, in some cases, lethal. However, many children survive the private hell of these "out of balance" familial power relationships and emerge into public life with a constellation of behaviours which are sometimes violent and frightening (bad), and sometimes odd or bizarre (mad). These behaviours or "symptoms" -- depending on the definition -- set them apart from their fellows. The power relationships in which they engage also depend on the status conferred by context. In the case of the mentally ill, their social shell is constructed from ideas of de-legitimation which include a psychiatric diagnosis but which may also incorporate other cues such as being of colour, being an immigrant, being female, being gay, being from lower class origins or being poor. The more low status cues, the more vulnerable and fragile the wearer's position. "He (or she) is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Thus, the mentally ill have acquired a stigmatized or "spoiled identity" and in the process, become members of a category of people who exist outside the universe of obligation, objects of pity and fear, and potential candidates for having "good" done to them.

However, as Wartenberg points out, outsiders (also alternatively called the subjugated or the oppressed) are never "absolutely disempowered" (p. 173). Even under extreme conditions of repression, they have some power or agency, as it is sometimes called. Indeed, society is often thought of as a rigid structure (in fact, Gil uses that term) which is defined merely as a set of reified societal constraints. Agency then becomes our individual attempts to get around, ward off or simply cope with these constraints. However, a more useful view of the agency-structure relationship is offered by Giddens (as cited in Archer in Clark, Modgil & Modgil [eds], 1990). From his perspective, structure is viewed as a set of rules and resources where only one part is constraint and agency is the extent to which knowledgeable human beings follow the rules and use the resources that structure offers. Outhwaite (in Clarke, Modgil & Modgil [eds], 1990) states that to have no choice does not mean that there is no action. In fact, madness, itself, has often been described as a form of protest because it is thought to "symbolize a great disquiet" (Foucault, 1965, p. 130) which challenges and disconcerts by upsetting the "natural" order. However, as Foucault points out, this form of protest is feeble and easily defeated -- usually through incarceration in a "total" institution as described by Goffman (1961).

Janeway describes three types of options available to those who are held under such totalitarian regimes. The first action that can be taken is acceptance. Complete dependence on a regime and its functionaries for the basics of life can mean that people simply acquiesce, repressing any sense of injustice before it rises to the surface and demands dangerous action. The choice of acceptance is a costly one that can result in utter defeat, creating a helpless and hopeless victim or an "institutionalized" patient (Goffman, 1961). The second possible action is to get out, leave, escape, get "well," or become "normal." Janeway argues that this is a particularly difficult route to take, not because the people who are caught in such circumstances lack courage but because they lack clarity. One of the powers of a total regime is it's ability to create and maintain stability through the deadly and ensnaring combination of fear and hope -- fear of their keepers' power and hope that this power may, after all, be turned to beneficial use. The third action available is "disguised disobedience" (Janeway, 1980, p. 199). Patients' protesting voices, as heard in the previous chapter, demonstrate a variety of forms of disobedience. Sometimes, after release, they wrote exposés of their terrible treatment while incarcerated in asylums. Others wrote of being ignored and neglected. One politely asked to be paid for the free labour she had contributed. Some attempted to influence the nature of psychiatric treatment by pleading for more humane conditions. I suspect, however, that the more common acts of disguised disobedience were those which I witnessed during my time in a contemporary psychiatric hospital – manipulation, trickery, verbal insults and, occasionally, physical attacks, most of which were interpreted as further signs of illness rather than the tactics of resistance.

These sorts of rebellious actions can annoy and perhaps even frighten but they are not a particularly effective way to create change. While society's outsiders may "possess a latent appreciation of how power works in the everyday world, and especially of what happens when it works badly" (Janeway, 1980, p. 14), what they don't know is their own strength. Outsiders, just like the more powerful insiders, learn about power from the position of helpless children. Both groups tend to define power in uni-dimensional terms, as limiting and thwarting and as result, both struggle with their own blind spots. Outsiders think of power as something everyone, but them, has. Given that they experience it as dominance, they conclude that it is something they do not want and withdraw in ignorance and isolation. For example, Wolfe (1993) criticizes current-day feminism for fostering a cult of victimhood. Victim feminists, as she calls them, glory in self-sacrifice, see one woman's gain as another woman's loss, and insist that all women have to "equalize downward" (p. 137) in order to be true feminists.

The powerful, who also tend to define power strictly as dominance, seek ongoing affirmation that they are not dominators. They long to be viewed as right and good and, while perhaps not always kind, nevertheless, possessed of a beneficent vision that renders their motives blameless – "the meeting of ardent minds in the springtime of belief is the highest award that the powerful can receive" (Janeway, 1980, p. 162). Should they not get a reasonable supply of gratitude, they can cut themselves off from their subjects and depend solely on each other to create the rules by which they will govern. "This distancing elevates them out of the human world and out of touch with their fellows, but it does not cure them of bad dreams" (p. 94). Janeway concludes that a loss of communication between the powerful and the weak "opens the door to fantasy and unreal expectations for both and interferes with the capacity of society to manage itself" (p. 94).

Power as a contractual relationship

The view that psychiatrists and other mental health professionals are merely instruments of social control is simply too narrow. First, it assumes that the only form of power relationship possible is dominance -- an understandable position to take given the saliency of dominant-subordinate relations in our society. Second, it ignores the idea of hegemonic control which renders power invisible to both the powerful and the powerless alike. Ideas of social control suggest that powerful people are aware of their superior status and consciously choose to use their power in a nefarious manner. The less powerful, on the other hand, are seen as mindless victims, unable to affect their fate in any way. Neither statement appears to be true. Third, it neglects the fact that there is a relationship between the powerful and the less powerful, one in which both groups play a role.

Janeway defines this relationship as a kind of power contract[1] and argues that "in politics, the governed consent to be ruled in return for an ordered, competent use of power that supplies them with a reasonably safe and stable environment and this consent frees rulers to act" (p. 111). She believes that both the powerful and the less powerful want this contract to work because when it does, it produces a society that functions successfully, or, in Gil's (1996) terms, one which meets basic human needs. For example, if patients were to get real, meaningful and timely help from psychiatrists and other mental health professionals, and if, upon discharge, they were able to obtain friends, family, a home and a job, they would be highly likely to view the mental health system as successful and the power contract as functional. However, as Janeway acknowledges, most of the time power contracts don't work, mainly, she believes, because those in power are isolated from their "subjects." In Foucauldian terms, they are cut off from the valuable popular knowledge which arises from the everyday experiences of those who are less powerful. Certainly, the history of psychiatry is one of dominant classes talking mainly among themselves without seeking or hearing the views of patients or ex-patients.

My experience of a psychiatric hospital seems to suggest another wrinkle that must be considered. In the hospital, there were a number of power contracts operating simultaneously. Powerful -- relative to the patients -- psychiatrists and mental health professionals routinely defined themselves as weak in the face of administrators, and administrators in their turn, defined themselves as weak in

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[1] In fact, Janeway uses Rousseau's term, "social contract," but this phrase has a particularly contemporary meaning in Ontario. In 1993, the New Democratic Party, which was then in power, negotiated what it called a social contract with its public sector employees and unions.The goal of the contract was to reduce wages and avoid lay-offs. It was a highly controversial move. Thus, in the Ontario context, "social contract" has acquired a substantially different meaning than what Janeway intends. I have chosen to substitute "power contract" in its place to avoid confusion.

the face of Ministry representatives. And while it was almost always true that the patients were the least powerful in this hierarchy of power relationships, overt violence and covert "manipulation" could momentarily alter even their lowly status. When people participate in a number of power contracts at any given time, their externally-defined power status (their shell) becomes contextually defined. Thus, depending on the situation, powerful people may not at all times be powerful nor are powerless people at all times powerless. However, Miller makes the case that, in our culture, an internalized sense of powerlessness is a stable norm for both groups in most situations.

Power as protest

Given that most power contracts do not run smoothly, resistance and rebellion is a constant threat. Janeway argues that, once the less powerful understand that the powerful value their loyalty and consent above all else, they have identified their most important protest tool -- mistrust. Thus, the first step in protesting the inadequate workings of the power contract is for outsiders to begin to refuse to accept how the insiders have defined them and develop their own self-generated identities. Do not aspire to be normal, she advises, for the stigmatized "break the rules by being, not by doing" Instead, "accept (and celebrate) the 'spoiled identity' in public, no matter how (you) feel about it in private" (p. 245).

However, even a large measure of mistrust coupled with the re-definition of a stigmatized identity cannot sustain protest if it is experienced in isolation from one's peers. The powerful exert an intense pressure on the less powerful to see their pain and suffering as of their own making instead of as the consequence of a flaw in either the powerful's ideas and actions or in the power contract itself. Therefore, the second step in mounting a successful protest is for those who are outside the universe of obligation to come together. "When individuals blend into a movement, individual goals become a joint purpose that won't be trivialized by self-doubt" (p. 174). The resulting sense of mutuality is emotionally rewarding and fosters a new sense of trust in oneself and one's peers.

Effective protests must, then, take a third step by developing a structure for their operation. The purpose of an organizational structure is to nurture leadership and facilitate communication so that the movement can consistently renew feelings of mutuality and translate the resulting energy into effective action. It is also the organization's job to create an ideology or creed that hardens the group's emotional and intellectual commitment to the cause. An ideology serves as a legitimizing symbol for the group's new and celebrated identity. It also provides a compass that charts the movement's course, a winnowing tool that allows members to sort through the myriad of complaints and issues it could take on, searching for priorities, and finally, it offers a rudder that steers members through and around the many competing ideologies of its allies and enemies so that their destination is assured.

In addition to Janeway's ideas there is, in fact, an entire field of study called social movement theory which has been developed to examine the genesis, strategies and fates of protesters and their movements. The utility of this group of theories lies in its ability to locate individual experiences within the concept of collective action. In other words, it will help, as have Miller, Janeway and Wartenberg, connect individual personal experiences to the wider arena of public politics and social change.

Historically, social movement theory grew out of studies of rebellions, revolts, uprisings and industrial conflicts (Melucci, 1989) -- the collective version of reactive counter-violence of which Gil (1996) speaks. Given that the exercise of early forms of dominance often employed force, countervailing measures, in their turn, tended to be violent. Issues of concern in these formative studies were confined to analyzing the conditions which moved people to collective action in the first place, the composition of a movement's membership, and the nature of the action it eventually took (Melucci, 1989). Generally speaking, social movements were seen as a form of "mob rule" and theories concerning them were heavily influenced by mass psychology (Neidhardt & Rucht, 1991). Later, as dominance itself took on more subtle forms, the mob became re-defined as only one form of rebellion (Wilkinson, 1971) making it possible to include non-violent protest in research activity (Neidhardt & Rucht, 1991). In fact, Gil (1996) credits these contemporary social movements, with their emphasis on democracy and justice rather than guns and swords, as the primary force that will eventually break the destructive violence-counter-violence spiral that characterizes our present social world. Certainly, the non-violent ideologies of Ghandi and then, Martin Luther King have led first, to martyrdom and second, to a powerful and enduring iconography that has created a valued place for non-violent protest in democratic societies.

The 1960s offered a remarkably fertile period for the study of all sorts of social protest activities. During this time, Killian (in Faris [ed],1964) was the first to suggest that movements were not the result, but the creators of social change.

Mayer (1991) points out that today, the term social movement embraces a multitude of social protest and reform activities; peace, environment, anti-racism, gay and lesbian, disability and the women's movement are just a few examples.

Contemporary protest has become part of the fabric of social life. Melucci (1989) argues that one of the hallmarks of these new sorts of movements is that members understand that symbolic change (often in the form of language) is an important precursor to real change. Second, they seek to make power visible. Thus, a clear understanding of the mechanisms and the uses of power becomes essential to the change process. Also, as Foucault states

> "the main objective of these struggles is to attack not so much.. an institution or power, or elite, or class, but rather a technique, a form of power... They are in opposition to the effects of power which are linked to knowledge, competence, and qualifications: struggles against the privileges of knowledge. But they are also in opposition against secrecy, deformation and mystifying representations imposed on people... What is questioned is the way in which knowledge circulates and functions, its relations to power. In short, the *regime du savoir*" (as quoted in Plotke, 1995, p. 116).

Finally, Melucci believes that these new movements "don't separate individual change from collective action" (p. 12). Members see their own individual transformation as integral to wider societal change. In other words, they make the personal political.

Plotke (in Lyman [ed], 1995) argues that the older forms of social movements aimed to capture political power and redirect it in a way that was more favorable to their collectivity. New movements, on the other hand, are "concerned mainly with quality of life issues, and with the definition and valorization of personal and collective identities" (p. 117). In short, they are interested in individual power and how its exercise can positively affect their relationship to the world or, as Gadacz (1994) would argue, in breaking the bonds of their colonized internal life-worlds so that they can participate in society as fully recognized and contributing citizens. In Janeway's terms, they insist on a power contract that works for everyone.

Berger (1977) -- an author who is not typically considered a social movement scholar -- provides an avenue for the reconnection of these ideas and theories to Janeway's prescription for effective power contracts. He argues that one of the casualties of modernity has been our formally sanctioned "mediation structures... institutions which stand between the individual in his (or her) private sphere and the larger institutions of the public sphere" (p. 132). Much as Janeway has argued, Berger believes that modern society divides social life into the hugely public sphere -- government, multi-national corporations and unions, for example -- and the small, private world of the individual. As a result, people feel alienated, in the Marxian sense of the word, and left on their own. Mega-structures, on the other hand, are cut off from those values and beliefs that people hold dear -- Berger calls it the general morality, Foucault calls it popular knowledge -- which must be understood if the powerful are to rule without resorting to coercion. He concludes his argument with two cardinal rules for the production of humane and meaningful public policy. First, it "should protect and foster mediating structures (and second), wherever possible, public policy should utilize the mediating structures as its agents" (p. 138). In Berger's terms, a protest movement is an example of an informally produced, "grassroots" version of a mediating structure.

The advent of new forms of social movements is portentous. Foucault (1977) argues that, historically, the industrial revolution transformed society's use of power by making it more efficient, less violent and orienting it toward capturing the mind instead of merely the body. Janeway believes that "the position of the weak (has always been) a barometer of change" (p. 3) while Gil insists that these non-violent forms of protest are the key to changing our structurally violent society. Alvin Toffler (1990), as a contemporary prophet of social change, states that, indeed, we have just begun another massive "powershift" which will affect us all and, as with the industrial revolution, this period of change "does not merely transfer power. It transforms it" (p. 4). The cause of the present powershift is the global availability of information and knowledge heretofore controlled and rationed by the powerful. The explosion of communication technology has meant the involvement of many more people in the production, consumption and criticism of society's erudite knowledge -- it's "truths." As knowledge is redistributed, so is power (Toffler, 1990). Also, what is done with knowledge, once it has been acquired, is different. Previously, subjugated groups sought knowledge in order to persuade those in power to treat them fairly and more humanely. Toffler (1980) states that, today, with relative ease we acquire vast amounts of knowledge whether or not we are actively seeking it and we are employing that knowledge in order to become a society of "prosumers." Prosumerism is the fusion of consumption and production whereby people bypass the traditional exchange economy developed as a result of the industrial revolution and develop "do-it-yourself" solutions to their own problems -- instead of paying someone to do it for them. Self help is an example of prosumerism at work in the health care field. In case we are inclined to minimize the importance of self help, Toffler (1980) argues that it represents a fundamental shift in our self-concept and in the nature of the professional-client power contract. Thus, while new social movements attack the *regime du savoir*, as Foucault terms it, the *regime* is, itself, on a path toward a "collision with tomorrow" (Toffler, 1990, p. 464). In sum, present-day protesters are protesting different things in different ways because society, itself, is different.

Power as liberation

Members of new social movements appear to be struggling towards a fundamental re-definition of the power contract and of power itself -- not just with simply improving on "the way things are." They not only want a power contract that works, they want a contract that is different in two important ways. First, their very presence as participants in a contemporary social movement is indicative of a newly recognized power contract -- one which is struck among one's peers, emphasizing equality. Gadacz (1994), argues that the social liberation of oppressed groups is intimately tied to this new form of power contract which he and others call empowerment. Empowerment is an individual process of self-liberation which he defines as "learning to overcome internalized expectations and attitudes of bitterness, helplessness, self-denial and alienation " (p. 104). Whitmore (as cited in Lord & Hutchison, 1993) offers four assumptions that generally underlie empowerment: "a) individuals are assumed to understand their own needs better than anyone else and therefore should have the power to define and act upon them, b) all people possess strengths upon which they can build, c) empowerment is a lifelong endeavor, and d) personal knowledge and experience are valid" (p. 7).

The process of empowerment usually begins by individuals getting angry or, more properly stated, becoming aware of their anger. An angry subjugated partner in any power contract immediately increases his or her relative power, although what is done with that anger ultimately determines whether or not the improved position is maintained. Self-determination and self-efficacy are central to empowerment – not the ability to get what one wants when one wants it. Thus, an empowered exchange involves both power and control, first over oneself and then over one's capabilities. In order for people to become empowered, they must acquire skills. They must also have the opportunity to try out new behaviours and the freedom to fail. Further, it is critical that they be supported by the external material resources which constitute the most basic of human needs, secure housing and an income, so that they can have at least some measure of control over their public, as well as private selves. As Janeway points out, avenues for action under totalitarian regimes are limited. Finally, Lord & Hutchison (1993) insist that no one can become empowered on their own. They must have the company of their peers, who like themselves are struggling, improving, regressing, and triumphing. They also need access to welcoming community environments such as self help groups, social action organizations, churches, schools, employment, friends and family.

Gadacz concludes that:

> "Empowerment as a developmental and transformative process is at the heart of a social movement... Reform and equality can only be pursued by empowered individuals who have learned and acquired action skills that

> enable them to play an ever-more conscious and assertive role in constructing their own social and political environments." (p. 95)

Wartenberg argues that the powerful, too, can liberate themselves. He concludes his work with a discussion of what he calls transformative power -- the ability to nurture, inspire or heal. In sum, "the constitution of the other as a more independent being as a result of the relationship itself" (p. 206). Liberating power relationships, like dominant ones, include, by their very nature, a power imbalance. However, with dominance, the focus is control of others for fear of what they may do, the goal is compliance, the justification is "for your own good" and the reward is gratitude regardless of outcome. With liberating power, the focus is the nature and quality of the power contract itself, the goal is mutual liberation (from dependency *and* from being depended upon), the tactics are guidance, encouragement, support and discipline, the justification is "for *our* own good," and the reward is congruence of intention and result -- in short, a power contract that functions. However, the important difference between power contracts based on dominance and those based on liberation is that dominant power relations produce dependent, fearful people who create rigid social structures that oppress. On the other hand, liberating power relations produce independent, confident people who create flexible social structures that support freedom.

The chart that follows illustrates the differences between power as dominance and power as liberation in a simplified form:

	Power as dominance	**Power as liberation**
Focus:	Control	The nature and quality of the power contract, itself
Goal:	Compliance	Mutual liberation
Tactics:	Coercion and punishment	Encourage, guide, support, discipline
Justification:	For your own good	For *our* own good
Results:	Dependent people and rigid social structures that oppress	Independent people and flexible social structures that support freedom

Wartenberg uses the Socratic method of teaching to illustrate what he means by liberating power relations. Instead of lecturing his students, Socrates presented them with a series of provocative questions designed to inspire a search for their own answers. In order to transform students into independent and self-aware human beings, Socrates chose not to invoke force or coercion which are the traditional expressions of domination. Instead, students were free to partake of the relationship or to leave it as they wished. In offering this choice, he created an atmosphere of trust which is absolutely essential to the exercise of liberating power. However, if teachers (parents, therapists, mentors, psychiatrists, mental health professionals) waiver in their dedication to the other's independence, they may invoke the use of coercion to maintain their relationship. And it is at this moment that we collide with the paradox of psychiatric "help" which enshrines in law the right to resort to coercion. Under these circumstances, trust is lost and the relationship must, by definition, revert to one of domination.

In conclusion

The discussions contained in this chapter make it possible for me to talk about power which is rarely employed as overt analytic currency but which is, nevertheless, often the disguised subtext of a lot of research activity in my chosen area. It also gives weight to the necessity of examining the "other" voice in the power contract which has heretofore been neglected. Further, it allows me to look at professional-client/patient and government-consumer/survivor relationships in terms of mutually constructed, contextualized power contracts instead of the traditional approach which tends to de-link dominant and subjugated groups and define their activities as merely a series of opaque, unilateral and temporally un-anchored actions. Finally, an understanding of power and power relationships connects the personal and private experiences of early childhood, family life, mental illness, psychiatric treatment, and consumer and psychiatric protest to the wider arena of society as a whole. It also recovers mental patients from the deviant and pathologized margins of social life and relocates them to a more central and mainstream position where they are seen as both the producers and the products of a global powershift that is affecting us all.

CHAPTER 4

A NEW POWER CONTRACT?

Since leaving Queen Street Mental Health Centre, I have learned that what goes on "up" at the Ministry, among other things, is the production of government policy. Boudreau (1990) states that the task of public policy is to find "politically powerful words... which have the power to rescue in times of crisis, words which can influence attitudes, change behaviour and redirect action towards new goals, new ideals and even the beginning of new 'more progressive' eras" (p. 1). She adds that it is through the medium of policy that government promises citizens logical, workable solutions to their most pressing problems. However, the making of social policy is rarely rational (Boudreau, 1987) and there are a tangled set of interests to satisfy (Simmons, 1990).

The present period of mental health reform began in 1988 with the publication of the Graham Report and, although Simmons (1990) argues that most of what the document says had been said before, in fact, the authors used two new words; *consumer* and *partnership*. Toffler (1980) would argue that the appearance of these words is not a particularly surprising event. Along with the rest of society, health care is undergoing a powershift. Steady and reliable access to all kinds of health knowledge has led to the rise of self help (prosumerism) and it has provided a nascent, but very real way for patients to augment or to circumvent altogether traditional health care services (Levin, 1988). In addition, patients are turning more and more to alternative forms of medicine such as herbal remedies, culturally-based healing rituals, massage and acupuncture-- to name only a few choices. Immen (1996) reports that yearly, up to one quarter of the Canadian population seeks treatment outside the publicly funded Medicare system, paying over one billion dollars for these sorts of services. These kinds of competitive trends, coupled with the perceived utility of attempting to apply business and market place solutions to the many problems Medicare faces (Rachlis & Kushner, 1994), have meant that governments and health care professionals have begun to call patients "consumers" and formulate health care policies which call for a partnership with this heretofore neglected group. In fact, I would argue that consumer endorsement of health care initiatives has taken on a new and powerful meaning, perhaps even the status of a legitimizing symbol (Wartenberg, 1990). In the context of government, Gusfield (1963) refers to this higher authority as a political symbol which, when invoked, has the capability of cloaking a wide variety of policies, ideas and even people with its "right and good" power.

Indeed, during the present period of mental health reform, the term partnership has become a powerful political symbol. The Ontario government states that its new partners, consumers and their families, will help create an improved mental health system (Graham, 1988). However, the historical reality has been that political symbols have often been used to create "misunderstandings" which disguise the same old agendas in fresh language. As Vaclav Havel has said "we have always believed in the power of words to change history... but the self-same word can be true at one moment and false at the next, at one moment illuminating, at another deceptive (as quoted in Boudreau, 1990, p. 1).

In this chapter, I discuss the types of economic and social trends that have led to the present period of mental health reform. I also examine briefly the recent history of mental health policy in Ontario and describe how the word partnership has come to enter our vocabulary. Presently, two sets of formally identified partners are involved in mental health reform. In addition to consumers and psychiatric survivors, families of mentally ill people have developed strong, and often oppositional views which merit examination. I then review both the Graham Report (1988) and the formal public policy document it spawned, Putting People First (1993) seeking examples of words which signal their agendas for change. Using aspects of the previous chapter's discussion of power, I conclude with a description of how psychiatrists and unionized mental health professionals view the policy.

Why now?

Every five years since 1930, the Ontario government has produced a policy, an analysis or a report that calls for changes to the mental health system (Simmons, 1990). Consequently, the present period of reform is not a sudden event. Instead, it is the culmination of a series of incremental changes which have been supported by an informal policy of what Simmons calls "the art of muddling through" (p. ix).

Albrecht (1992) defines the role of government as the "protector of the basic rights of citizens, conservators of the public trust, and regulators of the operating systems" (p. 84) which, in this latter case, monitor the delivery of mental health services. The government's intentions are expressed through policy and, as a result, interested citizens, psychiatrists, mental health professionals and now consumers, survivors and their families pore over these documents, which by any other standard would be judged to be quite boring, searching for signs of what the government might *really* be up to as revealed through what the policy does or does not say.

Presently, the entire Canadian health care system is undergoing a series of changes of which mental health reform constitutes only a small part. The generally accepted reason for these reforms is that our system of publicly funded Medicare costs too much. As an example of out-of-control costs, Rachlis and Kushner (1994) argue that the medical profession has formed an expensive and unhealthy alliance with the drug industry resulting in over-reliance and over-prescription of medications. Some prescribing practices actually cost tax-payers even more because they lead to harmful drug interactions that produce their own health hazards. Nancarrow Clarke (1990) adds that mood-altering drugs (tranquilizers and anti-depressants) are the most heavily and the most often mis-prescribed medications in Canada.

A further cost-related concern stems from the widely-espoused perception that government spending has precipitated a fiscal debt crisis of frightening proportions (Armstrong & Armstrong, 1996). Yet, in contrast, citizens have also developed an "extraordinarily heightened" set of social expectations as to what health care can deliver (Evans & Stoddard, 1994, p. 30).

> "we have become obsessed with health.... We do not seem to be looking for more exuberance in living as much as staving off failure, putting off dying. We have lost confidence in the human body. The new consensus is that we are badly designed, intrinsically fallible, vulnerable to a host of

> hostile influences inside and around us and only precariously alive."
> (Thomas as quoted in Renaud, 1994, p. 320 & 321)

As a result, there are always cries of "gaps in service" and "unmet needs" which constitute a never-ending supply of fuel for the entrepreneurial ambitions of health care providers. Doctors, who have been the most effective competitors for health care dollars, are seen as the cause of many of the cost over-runs. For example, Rachlis and Kushner ask, why spend 300 million dollars a year for physician-delivered psychotherapy when social workers and psychologists can (and will) do it for less?

In spite of these concerns, these authors argue that the methods by which we fund our public health system are "fundamentally sound.. and what really needs fixing is the unplanned, uncoordinated, and unaccountable way we deliver health care" (p. 3). For example, Evans and Stoddard (1994) state that the "scientific basis underlying all health services research is weak to non-existent" (p. 36). In 1992, Francis Lankin, former Ontario Minister of Health, startled a national audience by declaring that fully one-third of the medical care delivered in Ontario is inappropriate. This assertion sprang from a study conducted by the Institute for Clinical Evaluative Studies which was published in its Practice Atlas. Just one example of the study's findings were figures relating to hysterectomy rates. Researchers found that menopausal women living in one part of the province were eighteen times more likely to have an hysterectomy performed on them than women residing in another area (Rachlis & Kushner, 1994). Further, Renaud (1994) believes that "some of the best kept secrets of longevity and good health are to be found in one's social, economic and cultural circumstances" (p. 322). Indeed, in 1990, the Ontario Premier's Council on Health Strategy declared that "a safe non-violent environment, adequate income, housing, food and education, and a valued role to play in family, work and the community" have a greater direct impact on well-being than traditional health care services (Putting People First, 1993, p. 4). These broader health determinants, as they are being termed, are precisely the types of things for which my former patients vainly longed; friends, family, a home and a job.

The third reason for overall health care reform is that citizens have lost their unquestioning faith in professionals. In an example specific to mental health, Simmons (1990) asserts that psychiatry's "cavalier use of radical treatments" (p. ix) has led directly to a declining status for the profession. Dain (in Micale & Porter, 1994) puts it more strongly. He states that psychiatry "has violated the Hippocratic directive to do no harm" (p. 425). In addition, psychiatrists are no longer the sole expert voice they once were when asylums were run exclusively by medical men. Trained psychiatric nursing staff, originally called mental nurses, were introduced into Canadian asylums in the 1920s (Gibbon & Matthewson, 1947) followed by a number of other professions in the 1940s and 1950s. Each group has developed its own perspective on how to assist the mentally ill and, while psychiatry has retained its superior status in the hospital environment, the newcomers introduced a spirit of critique and effective competition that has only intensified over the years (Dickinson & Andre, 1988). Also, psychiatrists have seen their traditional seat of power, the institution, continually eroded by an ongoing process of deinstitutionalization. Further, the Mental Health Act has been incrementally liberalized, evolving from a law designed to protect society against the mentally ill to one which is intended to protect the mentally ill against the powers of psychiatry. The final, and perhaps most affecting change in the long term, is that supposedly less self-interested and more balanced bureaucrats, often bearing university degrees from other, less medically-oriented disciplines (psychology, nursing, social work and so on), have taken over senior civil service positions in the Ministry of Health -- positions that were traditionally occupied by medical doctors and psychiatrists (Simmons, 1990).

There is also one additional reason for the present period of reform which is specific to mental health; the impact of deinstitutionalization. In response to massive numbers of bed closures, government began to create a new avenue for the provision of mental health services -- a set of programs which, in thirty years, have grown to encompass 370 small, local community mental health services (Putting People First, 1993). Most are located in large urban centres like Toronto but a significant portion are scattered over the vast rural areas of the province. As psychiatric hospitals and institutions continue to endure attack for providing expensive, ineffective and sometimes harmful mental health treatment, community mental health services have taken on the new status of a viable alternative. They are seen as less costly than institutions, consuming only 10% of the mental health budget (Putting People First, 1993). Also, they are thought to offer more humane care in the preferred setting of the patient -- the "natural and good" community (S. Cohen, 1985, p. 35). Finally, they are mostly non-medical, concentrating on providing the kinds of things that the Premier's Council on Health Strategy said really mattered: housing, drop-ins, vocational support, and social recreational activities.

A brief history of mental health policy

In Ontario, there are three major reports which are thought to have contributed directly to the present period of mental health reform. The Dymond Report (1959), written in the latter part of the mental hygiene movement, stated that the key to providing effective help for mental patients was not to lock them away in distant provincial institutions but to establish a series of regional psychiatric clinics which would provide treatment locally, allowing people to remain at home in their own communities. However, most patients -- particularly those who were now being called the chronically mentally ill -- had no homes or communities. Thus, the report also paved the way for the creation of the Homes for Special Care program (1962), a for-profit enterprise which is still in existence today and which is funded mainly through its residents' welfare payments. The program has grown to include 719 homes, located mostly in rural areas, housing almost eleven thousand people (Simmons, 1990).

The Tyhurst[1] Report (1963), More for the Mind, decried the waning status of psychiatry in relation to other branches of medicine. The sub-text of the report's message was that psychiatrists must liberate themselves from the confining, stagnant back-waters of provincial psychiatric institutions (the once celebrated asylums) or else watch their profession wither and die. Mental illness, they argued, was exactly the same as physical illness. Thus, an enhancement of psychiatry as a profession depended on garnering an entree into general

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[1] In 1991, James Tyhurst was convicted of four counts of indecent assault and one count of sexual assault involving four of his women patients. It appeared that the assaults had occurred over a number of decades (Toronto Star, June 26th, 1991). He was sentenced to four years in jail. After the court case, it was revealed that he had never, in fact, earned a medical degree (Toronto Star, March 7th, 1992).

hospitals settings where "real" medicine was practiced and, not incidentally, where psychiatrists could acquire both the status and the paychecks enjoyed by medical doctors. Consequently, the idea of a few regional psychiatric clinics grew to include a more ambitious network of psychiatric inpatient wards attached to local general hospitals. By 1970, 42 such psychiatric units had been established (Simmons, 1990) and they formed the beginning of an embryonic community mental health system which, at the time, was defined simply as any psychiatric service that was located outside provincial psychiatric institutions. However, the plight of ex-mental patients, released by the thousands because of deinstitutionalization, continued to plague government policy makers. Boydell (1996) argues that the failure of both Dr. Dymond's and Dr. Tyhurst's version of community care created a new problem called "falling through the cracks" (p. 19).

The Heseltine Report (1983), Towards a Blueprint for Change, was published with the power of the media behind it. In 1982, the Minister of Health toured a typical Toronto boarding home located near Queen Street Mental Health Centre accompanied by Pat Capponi, an ex-mental patient and also a former resident of the home. The resulting media coverage exposed the wretched conditions in which ex-patients lived and highlighted the fact that most were not getting any community mental health services at all. Dr. Heseltine charged that the entire mental health system had been built on a tradition of sporadic government response to professional self-promotion rather than sensible planning and coordination. Consequently, the types of services that ex-patients needed most, such as housing, were woefully under-developed. In three years, the system acquired its own Ministerial administrative branch (Nelson, Lord & Ochocka, 1996) and it's funding base expanded from 13 million dollars in 1981 to 130 million by 1991 (Simmons, 1990).

This very brief history of the precursors to the present period of reform in Ontario recapitulates many of the power themes that have been part of the mental health field for two hundred years. The authors of the reports were almost exclusively doctors and psychiatrists, although they were sometimes joined by politicians. While the reports seemed to demonstrate a sincere desire to help discharged mental patients, some authors boldly promoted the interests of their own profession. In the end, each document prepared the ground for the next round of criticism. Confined by their own medical horizons, the authors defined *community* solely as the establishment of local hospital-based psychiatric wards and offered solutions in terms of more and more professional staff.

However, the Heseltine Report (1983), drafted with the indirect aid of a well-known but lone ex-patient advocate, demonstrated that, from the perspective of the ex-patients, the real meaning of community was not the provision of psychiatric services -- no matter where they were located. It was a decent place to live, food, friends, family, and a job. Consequently, community mental health became redefined as encompassing those programs which deliver mostly non-medical services such as supported housing, case management, vocational rehabilitation, drop-ins and crisis services. This new group of programs, with their initially small but eventually steadily growing funding base, became an attractive alternative source of employment for non-medical mental health professionals who were seeking work outside the medically dominated institutions and hospitals. Thus, general hospital psychiatric wards, the old provincial psychiatric institutions, the already established fee-for-service program that pays all independently practicing doctors, and the newer community mental health programs became the "four solitudes" that Ministry of Health bureaucrats identify as the administrative and management nightmare which is at the bottom of the latest round of mental health reform (Putting People First, 1993).

Partnership

In the mental health reform context, the present incarnation of the word *partnership* has its roots in a community mental health model called the Framework for Support (Trainor & Church, 1984). Boudreau (1990) states that this model is actually a Canadianized version of a number of American-generated service approaches which seek to re-define the community as a naturally supportive milieu. The ideological centre-piece of these models is the view that ex-mental patients are citizens and as such, have the right to participate fully in their own communities. Boudreau adds that a further intent is to end "the imposed hegemony of professionals over the system and instead, develop cooperative linkages between the professional and the natural helping systems" (p. 9). A natural helping system is defined as those supports and resources that are commonly available in any community. Specifically, the Canadian version of the model sees client/citizens as embedded in a four-component support network. Three of the components, self-help; family, friends and neighbours; and generic community resources (such as housing and general welfare) would be called "natural." The fourth and final component is the professional help offered by publicly-funded mental health services. A further development springing from this and other like-minded models is an attempt to enhance the status of the ex-mental patient now re-defined as a hybrid client/citizen and re-named a *consumer*. A final aspect of the Framework for Support model is the recognition that communities are, in fact, not all that generous when it comes to sharing their natural supports with marginalized groups. Thus, the model concludes with a call for a substantial change in public attitudes so that communities will begin to take up their proper role in supporting deinstitutionalized consumers (Pape, 1990).

An extension of this model is the advent of the word *partnership* which has been elevated to the status of a legitimizing political symbol so that it can be called upon whenever there is a need to demonstrate unequivocally the essential rightness of a plan or policy (Boudreau, 1990). This author adds that the choice of the word, "partnership" is particularly powerful because it offers the illusion of "consensus and frictionless solutions" (p. 12).

However, there can be no partnership without partners. Consequently, out of the Framework for Support model arose the notion that consumer and family groups were now the legitimate recipients of governments funds which would allow them to develop their own advocacy and self help groups (Trainer et al, 1992). Indeed, these groups might be seen as a version of what Berger (1977) calls mediation structures, available as a utilitarian bridge between the small local world of the individual and the meta institution of government. In fact, the Ontario government began a process of tacit endorsement of a concept called participation whereby all types of institutional and community mental health services were urged to actively recruit consumers as members of their boards of directors, committees and task forces. The stated intention of participation, in terms of the theoretical context of this research, is to create a liberating power relationship (Wartenberg, 1990) between government and consumers. However, Boudreau (1990) argues that a call to partnership can also be interpreted as a logical governmental response to some extremely difficult problems. As she sees it, these problems are fourfold; "1) the exhaustion of resources and allocation of losses; 2) the loss of faith in government and the consequent need to redefine the role of the State; 3) the loss of faith in professional knowledge and professional dominance; 4) the problem of overload in a pluralist and competitive democracy" (p. 12). These four problems add up to the perception that it may be the government's fault that Ontario citizens are paying for an expensive mental health system which is not working. And, it had better do something about it.

In sum, the promise of partnership is its potential to create a new type of power contract whereby previously excluded "consumers" are admitted into the inner circle of political decision-making with the goal of mutual liberation from dependency (for consumers) and from being expensively depended upon (for the government). However, in the midst of this seemingly good-willed plan for change is the reality that the government is the sole funder and, in the case of the provincial psychiatric hospitals, the direct employer of all sorts of expensive medical and non-medical mental health professionals who make their living by being depended upon. These professionals are well aware that their most dominant "partner" is government and are sharp-eyed when it comes to spotting a hidden agenda. Indeed, Hutchison, Lord and Osbourne-Way (1986), supporters of the Framework for Support model and anticipating resistance to the call to partnership, discuss the types of excuses mental health professionals might use to suppress or avoid real consumer participation.

> "They don't understand the technical language involved."
> "Our clients are happy the way things are."
> "We have no guidelines."
> "The clients aren't motivated." (p. 12-13).

They also identify what they call barriers within consumers but which Janeway would tend to call justified mistrust of the new agenda:

> "Our involvement has not been encouraged in the past, so we wonder why they want our involvement now."
> "We are afraid that if we speak out and push for changes, they might find some way of getting back at us." (p. 11).

Barriers and excuses aside, these authors insist that the transformative potential of partnership far outweighs its drawbacks. They argue that participation, aside from being the right of every citizen, offers consumers greater self respect and dignity and mental health professionals new insights into old problems.

Another group of partners

Adding to the complexity of the mental health reform process is a second set of partners -- the families of mentally ill people who have, themselves, begun to develop self help groups combined with political activism. In Ontario, there are several formally organized family groups: the Ontario Friends of Schizophrenics, the Mood Disorders Association, and the Family Association for Mental Health

Everywhere (FAME). Ontario family groups are vociferous critics of the mental health system.

Families often have an agenda for change which is in direct opposition to the concerns raised by consumers and survivors but the incompatibility of their respective viewpoints is never raised in official government policy. Families contend that not only do they have to deal with their relative's devastating illness and the social stigma that accompanies it, but attempts to get appropriate help are thwarted by a mental health system which they argue, like Rachlis and Kushner (1994), is unplanned, uncoordinated and unaccountable. They also feel that mental health professionals are trained in family-blaming treatment modalities and, as a consequence, exhibit hostile attitudes which engender alienation and guilt (McLean, 1990). In addition, they point out that, paradoxically, these same blaming clinicians discharge an estimated 72% of their patients back to their families (Marcus as cited in Boydell, 1996) and then when problems arise, tell them to "kick their relative out of the house" instead of offering help. In Ontario, families provide 60% of community care (Quality of Care Coalition, 1993) and, in Canada at any given time, approximately eighty thousand people with schizophrenia live with their families (Seeman as cited in Boydell, 1996).

Families state that they are not equipped to deal with mental illness and are desperate for information such as, what has their relative been diagnosed with? or what are the medications expected to do? Others feel that very real concerns for their own physical safety are completely ignored when their ill relative, known to have been assaultative in the past, is discharged from hospital without warning. While it remains true that most people with a diagnosis of mental illness are not violent, those who do assault often target family members (Arboleda-Florez, Holley & Crisanti, 1996; Monahan & Arnold, 1996). In fact, the level of violence towards family caregivers may be higher than heretofore suspected. In 1986, the National Alliance for the Mentally ill (NAMI), an influential American family organization, sponsored a survey which found that 38% of families reported that their ill relative had been assaultative in the home at least some of the time (Torrey, 1995). However, in a recent study of Toronto mothers who were caring for sons or daughters with schizophrenia, twenty-three of the twenty five respondents (92%) revealed that they had been assaulted by their adult child (Boydell, 1996). This researcher argues that societal norms assign caregiving functions almost exclusively to women and, as a result, it is mothers who are most at risk for assault. Additionally, suicide is a constant and realistic fear for families. Torrey (1995) reports that from 10% to 13% of people with schizophrenia kill themselves and from 15% to 17% of people with manic-depressive disorder or depression eventually die by suicide.

Family experiences such as these have led them to argue that it is really *they* who have born the brunt of deinstitutionalization (Isaac & Armat, 1990). Bowed down under the financial, legal and emotional burdens that can accompany caring for their loved one, families often state that they need help and support almost as much as their relative (Everett [ed], 1994). In addition, they want mental health professionals to understand that often, they are not just one of three forms of "natural" supports suggested by the Framework for Support (Trainor & Church, 1984). Mostly, they are the *only* support. Some go further, believing that government, as a cost-cutting measure, has simply shifted the burden of care from the institution to the family which, as Boydell (1996) points out, usually means exploiting the unpaid labour of women caregivers.

Finally, as a resistance strategy against blaming and stigma, most family groups are fervent supporters of the nature side of the nature-nurture debate. For example, in the United States, the National Alliance for the Mentally Ill (NAMI) has lobbied for schizophrenia to be reclassified as a neurological disorder, hoping that more funds would be made available for biological and genetic research (McLean, 1990). Members of this group insist that mental illness is exclusively a brain disease and has nothing whatsoever to do with environmental or family factors. They feel that they and their ill relative should be treated no differently than when a physical illness strikes.

In sum, the family position is that there are no social causes of mental illness, only social consequences. However, Boydell (1996) discovered that viewing mental illness as a neurological disorder was not the comfort it is supposed to be. The mothers in her study constantly questioned themselves about whether or not there was "something they could have done, should have done differently" (p. 127). They wondered if their child's problem had been caused by some sort of abnormality during pregnancy, a childhood illness, violence in the home, a divorce, an inattentive father or moving to a new town. In addition, Boydell found that, in fact, non-blaming attitudes on the part of mental health professionals didn't really help either. The mothers continued to feel responsible and guilty, secretly believing that if they could somehow change their own behaviour, their adult child would get well.

The view that mental illness is a brain disease also, apparently, leaves families unable to take effective action when their ill relative becomes assaultative. Violence becomes understood as an integral part of the illness. Boydell (1996) quotes one of her study's respondents as saying:

> "He started breaking things in the house and he hit me. He hit my mom once too and the police said, 'Do you want to lay charges?" ... Here is a mentally ill person. I am his mother. This is his grandmother. We want to help, not put him in jail. Of course we said we'd never (charge him) so you don't get any help. You don't get medical help and you don't get no help at all." (p. 161)

A public stand regarding the biological basis of mental illness and fears regarding assault and suicide have resulted in many family groups taking an advocacy position which supports involuntary psychiatric treatment. For example, some family groups insist that the Ontario Mental Health Act is far too liberal, leading to needless deaths because families can't force their ill relatives into hospital or insist that they take their medication. In addition, some families advocate for laws which allow for community committal, a concept which means that certain discharged patients can be placed under a legal order where they must take their medication, live in certain types of housing, attend programs, refrain from alcohol or drugs and responsibly manage their money, or else they can be forced to return to hospital (Boudreau & Lambert, I & II,1993).

Finally, as a counter-move against the links that have been made between experiences of child abuse and subsequent mental illness (Gelinas, 1983; Browne & Finkelhor, 1986; Steiner Crane, 1988; Silk et al 1995; Mullen et al, 1996), 4600 families in Canada and the United States have founded an organization known as the False Memory Syndrome Foundation, headquartered in Philadelphia. While the group acknowledges the existence of sexual abuse, they believe that commonly quoted statistics are greatly exaggerated. They charge that irresponsible and poorly trained therapists are "creating" memories in their clients by suggesting abuse has occurred when the clients, themselves, have not raised the issue (Bayin, 1993, p. 48). Indeed, sexual abuse has increasingly become a matter for the courts as allegedly abused children charge their parents with assault, and parents in their turn, sue therapists for creating false memory syndrome.

Given these sorts of family views and experiences, it is not surprising that their agendas for change run in opposition to those of consumers and survivors. Boudreau and Lambert (1993) argue that the split between family and consumers groups is based on "fundamentally incompatible discourses" (p. 80) with families most often arguing that psychiatry is helpful and no one should be deprived of its benefits while consumers usually take the viewpoint that psychiatry is harmful and people must be protected from it. On a deeper level, these differences appear to surround the issue of power. The family side of the debate believes that society is justified in forcing patients to accept psychiatric treatment because it's for their own good while the consumer side insists that they have the right to refuse psychiatric treatment -- even if it were for their own good -- "a civil libertarian versus paternalistic or *parens patriae* conviction: the collision of views is categorical" (Boudreau & Lambert, 1993, p. 81).

The making of policy

The making of government policy is a slow process, not incidentally because of the tangled and highly emotional sets of interests it is supposed to satisfy. In 1987, the Liberal government appointed former Canadian Mental

Health Association volunteer and retired engineer, Robert Graham, to head the development of an "action plan for community mental health" (Simmons, 1990, p. 264). The Graham Report (1988) heralded the beginning of a new approach to policy making. As Simmons (1990) states, "No longer will policy emerge out of cozy deliberations amongst a small circle of politicians and bureaucrats" (p. 267). Indeed, the members of the committee that developed the Graham Report included both medical and non-medical mental health professionals, but it did not include representation from the new partners -- consumers and families. Instead, their views were sought through a series of consultations which were conducted by the central committee. Seven regional meetings were held where all interested individuals and groups, including consumers and families, presented position papers and briefs. The committee also received 152 written submissions. In a study of a parallel consultation process, Church (1993) reports some of the tensions inherent in the troubled new partnership:

> A professional speaks,
>
> We were yelled at. I remember (a person) shouting from the back of the room: 'We are going to make you people hear us. Don't ever forget it. Damn it!' ... And I went to bed that night and I was very upset. I couldn't sleep in the hotel. Because I did not come to work on these things to be yelled at. (p. 212)
>
> Another adds,
>
> They were allowed to stomp out of the room. They were allowed to tell us we were assholes... there were occasions when you would have liked to tell (them) off. (p. 215)
>
> Consumers and survivors responded with:

> I don't have much sympathy for professional sensibilities.. our guys are starving and dying and these guys have hurt feelings. It is really hard to swallow. (p. 226)

Clearly, the new partnership was creating a different atmosphere than heretofore had been typical for the production of government policy. These sorts of interchanges indicate a shift in the power contract. Consumers and survivors, whether or not they were aware of it, were beginning to take on a much more powerful role than had previously been the case. While yelling and calling people names are not the types of empowered tactics that are expected to net marginalized groups positive gains in the long run (Gadacz, 1994), they are nevertheless a demonstration of agency (Wartenberg, 1990) and an indication that there was, at least, the potential to turn the traditional relationship between mental health professions and their former patients on its ear. Clearly, something was happening.

Out of these sorts of uncomfortable, emotional, confrontative presentations, the Graham Report emerged. Given the different processes that had produced it, it might be expected that the report, itself, would be different but Simmons (1990) believes that it defined the problems in the mental health system much in the same way preceding reports had. The Graham authors stated that there were no coherent mental health plans that identified who should be served, what services they should get, how these services should operate or where they should be located. The main issue, they said, was that there were wide regional disparities in service provision and where services existed, there were "gaps."

The solutions offered highlighted a number of words. *Planning* was by far the most heavily emphasized requirement of a reformed mental health system. The Ministry of Health, the provincial psychiatric hospitals and the District Health Councils all needed to develop plans, and they required funds to support themselves in these activities. Also, the plans had to be multi-year and multi-layered (provincial, regional and local).

A second important word in the Graham Report was *community-focused.* This idea meant that programs, whether delivered through hospitals or through community mental health agencies had to embrace a community philosophy, meaning they had to be less illness-oriented and more dedicated to broader health determinants. Drawing upon the Framework for Support model, the report suggested placing formal government-funded mental health services fourth in the aforementioned list of supports. The Graham Report also defined precisely which functions (rather than which programs) must be included in a complete mental health system; identification, treatment and crisis support, consultation, coordination, residential support, case coordination and case management, social support, vocational support, self help/peer support, family support, and advocacy. In order to provide these functions, the authors called for a greatly enhanced community mental health system whose funding and standards would be regulated through legislation -- legislation which would have to be drafted as none existed. It also suggested training for everyone, but especially for psychiatrists so that they could prepare themselves for roles in a community-focused system.

The third set of words emphasized by the report was *seriously mentally ill.* Serious mental illness was defined according to what are called the three D's;

diagnosis, disability and duration. Naming the "target group" (p. 20) is a practical beginning point of many policies or reports because the size of government's fiscal obligation is dependent upon exactly how many people are entitled to its services (Simmons, 1990). However, another major factor in this decision was the clear message that this group of people have been neglected by previous attempts at reform. In addition to the severely mentally ill, several special needs groups were identified in an attempt to begin to acknowledge the diversity of Ontario's population and also endorsing indirectly the belief that people's gender, ethnicity, race and age affects their mental health -- a view which, again, is typical of an emphasis on broader health determinants.

Next, the report emphasized the word *local* and in this way, it is very much like its predecessors. The Dymond, Tyhurst and Heseltine reports each recommended that mental health services should be decentralized and made available throughout the province so that people could have access to help no matter where they lived. However, Ontario has what the Graham Report defines as a "rural/urban dilemma" (p.25) -- extremely densely populated areas along its southern borders coupled with vast northern regions that are sparsely inhabited. Providing services under these conditions is extremely difficult. Thus, the report also highlighted the words *coordinated, integrated* and *accountable* indicating that the government needed some sort of a management strategy so that it could oversee the expenditure of its money in the proposed decentralized and much-expanded community mental health system. In service of this goal, the report suggested establishing a series of Regional Authorities which would be responsible for developing the proper programs in the proper locations. It also recommended a variety of training and recruitment strategies to ensure the migration of qualified mental health professionals to less desirable rural areas of the province.

The final word mentioned by the Graham Report was *partnership*. The report's recommendations were to be accomplished through a partnership between "consumers, their families, service providers and government" (p. 6), although the authors were mute as to how this partnership was to be fostered or implemented.

The Graham Report was a curious blend of less government, in favour of self help and informal supports, and more government, layering on of new bureaucratic structures to counteract regional disparities and to ensure coordination and accountability of the formal service network. The explanation for this seeming paradox lies in the fact that the report was written in a time of altering attitudes combined with a booming economy -- a time when it appeared that all things were possible. It also heralded a new and powerful emphasis on the bureaucratic lens which, in contrast to the medical viewpoint, tends to see things in terms of administration and management.

Shortly after the publication of the Graham Report, the Ontario economy came to a grinding halt, plunging this perennially prosperous province into a deep and long-lasting recession. The cadillac system designed by the authors slipped further and further from grasp and many of its deadlines for implementation passed. The recommended community mental health legislation never materialized. The idea of establishing regional authorities appeared destined for the dustbin. This is not to say that *nothing* was done -- far from it. Extensive planning for mental health reform, involving hundreds of mental health professionals, consumers, psychiatric survivors, families and many, many others, has been underway all across the province since the report's publication.

In 1993, five years later and right on target according to Simmons' five-year timetable for the production of mental health reports, the government released its formal policy document, Putting People First, which, although ostensibly based on the Graham Report and the legislative hearings which it spawned (Nelson, Lord & Ochocka, 1996), migrated considerably in both its tone and content, supposedly in response to the new fiscal reality. The policy was written by a team of bureaucrats with no attributed authorship. It also used a new term for consumers, referring to them as *consumer/survivors* (Reville & Church, 1990) in deference to the development of a more vociferous and radical branch of consumer activists who call themselves psychiatric survivors. The notion that the government was prepared officially to call the recipients of its own services, *survivors,* was greeted with anger in medical quarters. Psychiatrists stated:

> "The term 'consumer' implies caveat emptor and, accordingly, makes no accommodation to the legal and ethical relationship of doctor-patient. By accepting this description, the Ministry would seem to be abandoning the relationship of trust that society has evolved in the general interest of professionally based patient care and confidentiality. The term 'consumer' lowers the relationship to that of the marketplace and serves to weaken the Ministry's case that its policy is aimed at 'putting people first.' Using the term 'survivor' denigrates the services provided by professionals in the health care field." (OPDPS, 1994, p. 7 - 8)

In Putting People First, the problems with the mental health system were re-defined in light of recessionary trends and a perceived decline in the tax base. Expansion of the system was out of the question because the province was now grappling with overall health care reform based on the criticisms that began this chapter. The policy's authors concluded, not surprisingly, that funding for current mental health system was adequate but existing fiscal resources needed to be re-distributed as many mental health programs were providing the wrong type of service to the wrong people in the wrong location. As a result, an important word in Putting People First is *reallocation,* defined as ensuring that "whenever funding and patients are moved from institutions into the community, the workers who provide direct care will have the opportunity to move with the services and work in the community" (p. 27). In order to accomplish what, in essence, is a reallocation of jobs, the policy calls for a "comprehensive human resources strategy" (p. 14) but does not offer further details. It does, however, specify a time line; mental health reform will be concluded by the year 2003 when one half of the psychiatric hospital beds in Ontario will have been eliminated and an enhanced network of community services will be in place. In the process, the present configuration of 60% of funding for institutions versus 40% for community programs will be exactly reversed, creating a *balanced* mental health system.

A second problem with the mental health system, the policy states, is its four solitudes; the psychiatric hospitals, psychiatric wards of general hospitals and other specialty psychiatric hospitals, community mental health programs and fee-for-service physicians. The authors argued that these four solitudes had created an un-manageable maze where both duplications and gaps in service were common. Thus, another word that figures prominently in Putting People First is *system.* The policy calls for new linkages among the four solitudes that will create a coordinated and integrated continuum of care. And, in deference to *cost-effective*, a new word that Putting People First introduces, the establishment of new mental health services are to be confined to just four elements (as opposed to the Graham Report's eleven "functions"); case management, 24-hour crisis intervention, housing and supports and programs run by consumers, survivors and family members. The last element refers to a concrete demonstration of the government's commitment to its new consumer partners -- a program called the Consumer/Survivor Development Initiative which, in 1991, received 3.1 million dollars to develop self help and economic development projects especially for consumers and psychiatric survivors.

However, by far the most important word in Putting People First is *manage*. The policy states the Ministry of Health intends to take a new role as a "system manager" (p. 20) so that its many institutional and community programs are linked, coordinated, integrated, cost-effective and accountable. The new management ideology also promises to eliminate duplications, deal with gaps and generally sort things out so that the new system begins to run with clock-like precision.

There is a word, however, which is conspicuous because of its absence. Nowhere is the term *partnership* mentioned. Consumers and their families are invited to be "involved" (p. 9) and "help" (p. 13) but their new-found status as "partners" seems not to require official acknowledgment.

As a final and salient note, it is important to acknowledge that the intervening years between the writing of the Graham Report, the production of Putting People First and the present have been ones of substantial political change in Ontario. When the Graham consultations began, there was a Liberal government in power and its elected officials were noted friends of community mental health initiatives with Premier David Peterson doubling funding to this relatively new service area during his term in office. In the summer election of

1990, the supposedly secure Liberals, in an astounding upset, fell to the socialist-leaning New Democratic Party, signaling what appeared to be a shift to the left in Ontario politics. However, not long after his election, the new Premier, Bob Rae, who under normal circumstances would have been considered even more of a friend to mental health concerns than his predecessor, was judged to have traitorously abandoned his left-wing ideology and his party's labour roots as he wrestled with a deep economic recession and a perceived fiscal debt crisis (Walkom, 1994). In a second political upset five years later, Rae's own government went down to an humiliating defeat in June, 1995 when a disgruntled, recession-weary voting public opted for the exceedingly right wing agenda of the Conservative Party led by Mike Harris. This government had enshrined its political intentions in what it called the "common sense revolution," and very soon into its mandate, instituted billions of dollars of unprecedented cuts in government spending, coupled with a reduction in personal income tax. However, the common sense revolution had identified health care as sacrosanct and vowed that spending would remain exactly the same (Toronto Star, Sept 28th, 1995), although a program of hospital closures and reallocation was expected to address perennially lamented "gaps" in service. Presently, the Conservative government's formal position is that mental health reform will proceed as planned (Johns, October 27th, 1995).

However, deep cuts to welfare (21.6%), a policy of "workfare," a moratorium on new subsidized housing projects, deep cuts to training and education programs and the immediate repeal of the Advocacy Act (Guiffreda, Personal communication, December, 1996), have affected, what some would call, a central component of mental health reform policy; its emphasis on broader health determinants. In addition, community mental health programs have been hit with an across-the-board cut to their budgets of 2% with an additional 3% pending. Nevertheless, relative to the carnage experienced in other service sectors, these are small changes for mental health. The Consumer/Survivor Development Initiative remains intact. In addition, most consumers and survivors collect their social assistance through a disability pension called Family Benefits and it has not presently been cut. And mental health reform implementation planning has been stepped up, complete with new, supposedly non-negotiable deadlines.

While the powerful words that formed the basis of reform plans and policies remain the same, and <u>Putting People First</u> continues to be held up as the blueprint for mental health reform in Ontario, the political ground underneath these words and plans has shifted dramatically. The concept of *cost-effectiveness*, at one time considered only one component of formal mental health policy, has attained superior status in light of the many changes the Conservative government has introduced (Verlaan, 1995). The present research project covers a three year period, from January 1992 to January 1995 and, as such, reflects some of these shifting trends but it must be noted that respondent interviews, whether conducted before or after the rise to prominence of the Conservative government, maintained the same themes.

The forgotten partners

The changing political winds notwithstanding, <u>Putting People First</u> was, endorsed, understandably, by the community mental health sector through the medium of this group's provincial association, the Ontario Federation of Community Mental Health and Addictions Programs[2]. The policy, at least in surface intent, implied that these services were to be the favoured recipients of the new funding reallocation strategies, engendering entrepreneur-like visions of expansion heretofore considered only a dream. Thus, community mental health professionals were not necessarily concerned with competing vigorously for a visible partnership status with government, having concluded that their battle for recognition was over and won. However, Putting People First was not well received by the government's traditional and, now, seemingly former partners; psychiatrists, hospital workers and the 10,000 unionized staff of the provincial psychiatric hospitals represented by the Ontario Public Service Employees Union (OPSEU). The anonymous authors of Putting People First state that, this time, mental health reform will work because the professionals in the system are committed to cooperating with the proposed changes. The doctors countered that mental health reform means job-loss, pure and simple, and insisted that, without an attendant massive re-training strategy and transitional funding, cooperation would be highly unlikely (OPDPS, 1994). In a strong "hell-no-we-won't-go" message, unionized workers added that community mental health agencies, which are supposed to become the new employers of reallocated institutional staff, are rarely unionized themselves, are notoriously under-funded and offer benefits and working conditions inferior to those of public service employees (OPSEU, 1991). In addition, they point out that Putting People First doesn't even mention the cavernous 25% wage gap between the institutional and community sectors (Hay Management Consultants Report, 1991).

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[2] I was a member of the Board of Directors of this organization during this period and, thus, bear personal witness to these claims.

Putting People First stated that reform plans were based on an extensive process of consultation with consumer/survivors and their families. The doctors argue that the use of the term consumer/survivor is insulting and, while not opposing patient or family involvement in reform, they decry the lack of acknowledgment for the fact that institutional staff are also "partners." They contend that the Ministry's policy has created a false dichotomy -- an institutional versus community based services atmosphere which contributes directly to the four solitudes it criticizes. The union added that Putting People First is simply a plan for expenditure control. Under mental health reform, the provincial psychiatric hospitals will become nothing more than "warehouses for the severely ill and jails for dangerous patients" (Dukzsta as quoted in OPSEU, 1994, p. 7).

Putting People First stated that mental health reform will work because the Ministry of Health had extensively studied experiences in other jurisdictions and, as a result, developed a plan which built on what they had learned. The doctors said that the ideas the policy proposes are "more a matter of applied political skill than of mental health requirements" (p. 4). They added that what other jurisdictions actually discovered was the fact that "the transition from psychiatric facility-based care to the community has resulted in large increases in the homeless mentally ill population" (p. 4). Families join the doctors in these latter concerns, believing that a decreased role for hospitals and institutions will mean that their relatives won't be able to get the help they need when they experience crises (Beeby as quoted in OPSEU, 1994).

Putting People First states that an important key to the success of reform is to build on existing effective community programs. Doctors counter-argue that "community agencies have not demonstrated the will or the capacity to handle chronic or severely ill patients (p. 4). The union adds that community mental health in Ontario means "under-funded, under-staffed and over-burdened services.. struggling to cope with growing caseloads on shoe-string budgets" (OPSEU, 1991, p. 2). Inadequate budgets mean low staff salaries which translate directly into poor quality of care for patients and clients. In addition, both groups agreed, and were supported in their views by independent policy analysts (MacNaughton, 1992), that community programs have to be beefed up *before* institutions and hospitals are downsized or else there would simply be a repeat of the many ills associated with deinstitutionalization in the 1970s.

Finally, the policy states that mental health reform will work because "we have set realistic and achievable targets" (p. 8) coupled with appropriate timelines for their achievement. Doctors insist that Putting People First is essentially a "document for administrators" (p. 3). It talks in terms of budgets and beds per hundred thousand and neglects real issues like treatment and the roles of health care professionals. They conclude that the policy is simply a prescription for pulling precious funds from direct service delivery in favour of layering on expensive bureaucratic structures, reflecting an entirely self-serving attitude on the part of the bureaucrats who penned the policy in the first place. In sum, these critics believe that Putting People First demonstrates all too clearly exactly which people it intends to put first.

In conclusion

The proximate context for the rise of consumer and psychiatric survivor activism is the present period of mental health reform as defined by the Ontario government's official policy, Putting People First. The stated intention of recruiting "consumer/survivors" as partners is the creation of an improved mental health system where people can get appropriate help, when and where they need it. However, doctors and unionized hospital workers argue that this new partnership has been formed at their expense and that its stated goal of creating a cost-effective, balanced and well-managed mental health system is, in reality, a justification for job loss and lay-offs for workers with a concomitant rise in status of bureaucrats and administrators.

The present research project is played out against the backdrop of the power struggle that mental health reform has become but it is in no way confined to the narrow parameters of official policy. A principal goal is to examine the new partnership that government has attempted to create with consumers and psychiatric survivors, along with the altered power relationships it implies. While it is clear that government sees consumer and survivors as its new partners, it is less obvious how they, themselves, define their relationship to government. Is it true that consumers and psychiatric survivors sense the advent of a new power contract?

CHAPTER 5

RESEARCH METHODOLOGY

The sociological research enterprise rests on three interrelated components. First, there must be a question that demands an answer, at least from the researcher's perspective. Second, there is typically, although not always, a theoretical context which serves as a navigational aid. And finally, the researcher must settle on a particular method for collecting the data that serve as the raw material from which some sort of answer is derived (Denzin, 1989). The broad question which drives the current research rests in the fact that the involvement of large numbers of consumers and psychiatric survivors in the present period of mental health reform is an historical first. How they have re-constituted their identities, formed groups for social and political action and how they relate to government are questions that demand answers. The context for the research is twofold. First, the data must be read against the background of a mental health system which has accumulated two hundred years' worth of history characterized by cyclical urges to reform itself and second, against a multi-faceted present-day attempt which appears even more complicated than its predecessors. The theoretical framework for examining the data that result is composed of ideas about power and power relationships.

The purpose of this chapter is to provide an overview of the research methodology that I used to collect the data that form potential answers to my questions. First, I review in more detail, the questions that form the basis of the research. I then discuss the traditional psychiatric choice of quantitative measures, making a case for the utility of qualitative methods in general, but particularly in relation to the present study's theory base and the questions it asks. Subjectivity is given special meaning in qualitative research and although the first chapter of this work is designed to address this issue in a practical sense, I include here a brief theoretical discussion of its relevance. I also discuss the respondent selection process, my methods for data collection and analysis, and interviewing techniques. I offer a composite picture of my respondents as a preliminary introduction to the research results and I conclude with a discussion of ethical issues.

A review of the research questions

Historically, the views of mental patients and ex-mental patients have been invisible relative to the dominant discourse of psychiatrists, other mental health professionals, philanthropists, politicians and government bureaucrats. The present study is an attempt to focus on these ignored views by examining a number of questions.

The first two research questions arise directly out of my own experience of a psychiatric hospital where I learned that mental patients never change and don't get better. Today, many former patients are members of Ministry committees and Boards of Directors. Many direct their own self help projects and, in some cases, run government-supported businesses. I want to know how they got here from there. Specifically, the present research asks how have ex-mental patients come to re-define themselves as political activists (consumers and psychiatric survivors)? Second, how have they translated their personal experiences into a collective identity focused on political action? The third question is related to the present period of mental health reform. How do consumers and psychiatric survivors define their relationship to government given that it tends to speak of them as its partners? And the final research question stems from my examination of the history of insanity where it has been made amply clear what psychiatrists and other mental health professionals believe mental illness to be -- or not to be -- combined with a myriad of ways to fix, cure, treat or rehabilitate patients and clients. But what do consumers and psychiatric survivors, themselves, think mental illness is and what do they think should be done about it?

Selection of methodology

To date, most psychiatric research has focused on first, the bio-medical etiology of the "pathology" that is believed to underlie mental illness and second, on the development of various types of treatments and interventions. In addition, psychiatry usually prefers quantitative and therefore, reductionist research methodologies which tend to locate problems exclusively within individuals to the neglect of wider social contexts (Cohen as cited in Trainor & Boydell, 1994). Quantitative methods rest on positivist assumptions, summarized by Lincoln & Guba (1985) as the whole is simply the sum of its parts with the parts studied independently of one another; somewhere "out there" there is Truth and it's the researcher's job is to find it; researchers, as persons, are separate and apart from what they are researching; what is true here and now can also be true anytime and anyplace; there are no effects without causes and no causes without effects; and finally, researchers are objective and unbiased.

However, research is an engine that drives the production of knowledge and Foucault (1977) argues that knowledge is intimately tied to power. Thus, the conversion of people's minds, identities and behaviours into "medicalizable objects" (p. 175), aided by narrowly focused quantitative research measures, has the effect of removing them from the public sphere in preparation for capture by professional interests. Wartenberg (1990) would add that the "truths" produced through psychiatric research have the potential to create systematic misunderstandings which aid the process of dominance by quelling resistance.

On the other hand, Trainor and Boydell (1994) suggest that psychiatrists may, in fact, consider themselves to be powerless in their own milieu, suffering from a marginalized position in relation to the medical profession as a whole. Thus, psychiatry has borrowed heavily from the natural sciences in an effort to improve its status by appearing more scientific. Paradoxically, they have embraced "increasingly archaic ideas about what constitutes knowledge and how to pursue it" (p. vi) at a time when their medical colleagues are actually adopting more creative and innovative research methodologies, many of which are qualitative in nature. Thus, as psychiatrists burrow deeper and deeper into brain topography and chemistry, medicine is developing an interest in understanding patients as whole social beings. These authors add that psychiatry also may resist qualitative methods as a self-protective measure. Given that the Mental Health Act requires them, under certain defined circumstances, to treat people against their will, it is understandable that they may have no desire to understand their patients as human beings in case this kind of holistic knowledge interferes with their ability to conform to their legal obligations. Finally, it has been amply demonstrated that it is within the realm of patients' lived experiences -- their everyday lives -- where the disparity between the intention of psychiatric treatment and its sometimes harmful outcomes rests (Goffman, 1961; Estroff, 1981). In other words, research methods which view experience and meaning as appropriate objects of study form a distinctive epistimology that observes either different realities, or different aspects of the same reality (McCracken, 1990). Consequently, they have the potential to challenge the status quo and threaten power relationships which are based solely on dominance

Until recently, the few existing examples of qualitative research in the mental health field were generated by "outsiders" and the impact has been disproportionate (Trainor & Boydell, 1994). Goffman's work, Asylums, is often cited as a significant factor in deinstitutionalization. His ability to see patients as people, just like everyone else, touched readers deeply. Twenty years later, Estroff (1981) spent two years among clients of a Wisconsin community mental health program studying, documenting and sympathizing with the hardships they endured in an unwelcoming and violent deinstitutionalized world. Her work has shaped thinking in the community mental health sector.

Currently, qualitative research methods have begun to appear in a small way in the type of clinical psychiatric research which seeks to understand patients' own views of self and identity in relation to their mental illness (Strauss, 1989). The promise of this research is its potential to capture a better understanding of clients' problems through deeper level assessments, more accurate diagnoses, and improved treatment plans. However, if the sub-text of this activity is merely to identify which of the patient's life experiences are indicators of pathology while explaining away significant environmental factors integral to the experience of illness, its promise remains unfulfilled, leaving patients with a "curious sense of being listened to and ignored at the same time" (Trainor & Boydell, 1994, p. x).

The advent of community mental health services has spawned a myriad of mental health research projects and approaches which evaluate programs, develop service models and, to a lesser degree, assess efficacy. Like psychiatry, these types of research endeavors have also tended to focus on reductionist quantitative methods, favoring standardized measurement tools for data gathering which assign numbers to concepts like quality of life while ignoring clients' subjective experiences (Boydell, 1996). This author adds that it has been her experience that the "real" research outcome is often contained in the informal conversations surveyors have with their subjects after the required data has been collected. These conversations reveal factors which threaten the status quo of the traditional professional-client power relationship by highlighting the disparity between what the community mental health program intends and actual client outcome. These concerns have led to a nascent research trend which involves clients in program evaluation in the formalized role of "consumer," employing qualitative methods in order to seek evidence of customer satisfaction (Boydell & Everett, 1991; Everett & Boydell, 1994; Clarke, Scott & Krupa, 1993).

However, consumers, psychiatric survivors, women, ethno-racial groups, families and others remain dissatisfied with the state of mental health research in general (OMHF consultations, 1994). They are calling for an increased profile for qualitative research believing it to be a more egalitarian form of knowledge production. They argue, as does Foucault, that traditional psychiatric research appropriates and perverts their life experiences in the service of a professional self-promotion strategy that has nothing to do with their health and well being.

Thus, the selection of qualitative methods for the present study is, in fact, a political decision which acknowledges the power of the research act. The potential of qualitative methods is to engage respondents and researcher alike in a liberating power relationship with the goal of producing mutual understandings. Qualitative methods also seek to produce a research outcome which is congruent with respondents' understanding of their own reality. In sum, qualitative methods ask respondents to teach the researcher about their lives. In turn, the researcher's task is to describe and analyze the resulting data and to convey this mutually-produced story to readers.

In addition to satisfying power relationship concerns, qualitative methods are particularly compatible with the global nature of the present study's questions. They are "large" issues which, in the way the questions are asked, defy reduction to quantitative measurement. Additionally, the manner in which they are posed calls for process *and* content answers. In other words, they ask how and why, as well as what. Qualitative methodology is well suited to the process of exploration and discovery without imposing a priori hypotheses. Further, the present research questions are contextualized by both place and time and, as a result, are enriched when room is allowed for a variety of nuances, inter-dependencies and complexities to emerge (Patton, 1990). Finally, and perhaps most important, the study of the politicization of consumers and psychiatric survivors is an embryonic field and, as such, lends itself to "whole picture" research methods which can offer a fuller view of the topic. The logical first step in a new field of study is to develop a sense of the subject as a whole. Qualitative methods are highly suitable to this task. Once the territory is mapped, focused studies of isolated and discrete aspects may well be an appropriate next step.

Subjectivity

Qualitative methodologies demand that researchers identify and include their own personal perspectives and biases as an integral part of their work so that findings can be evaluated in the light of knowledge of the researcher, herself (Patton, 1990). The reason for the emphasis on subjectivity is that the assumptions which underlie qualitative methodology are precisely the opposite to those of quantitative methods: The whole is greater than the sum of its parts and must be studied holistically; there is no Truth out there to be found, only people's different realities; researchers and their respondents affect one another and thus, are interdependent; everything influences everything else all the time so it's impossible to talk about causes and effects; and researchers are human beings just like everyone else -- their values and beliefs influence their subject matter, their methodologies and their interpretations. In essence, a researcher's subjectivity, her consciously constructed view of the social world, is intimately tied to the research product. Thus, it was my task to begin this work with my own story, as it specifically relates to the study topic.

Also, qualitative researchers are their own research instrument. They become a part of both the subject they are studying and the process by which it is studied (Adler & Adler, 1987). In my case, the current research project offered a particular challenge in that, within the field of study, I occupy the same space, time and context as do my respondents. I am not a consumer or a psychiatric survivor. However, I am a mental health professional providing mental health services. Therefore, both I and my respondents are intimately involved in the mental health system, as well as in the many activities related to present mental health reform efforts in Ontario. Many of the consumers and psychiatric survivors featured in this study are people with whom I have some form of established relationship; as friends, acquaintances, former clients, co-workers or as fellow committee or Board members. Therefore, it is particularly important for the integrity of the research outcome that I define as clearly as possible who I am and what I believe in.

In the case of the present research, my own biases arise from three sources; my own personal and professional experiences, my studies of the history of mental illness, and my belief in the restorative utility of the consumer and psychiatric movement for my own psychotherapy clients. First, my experiences as a psychiatric social worker have left me with a level of skepticism regarding the efficacy of inpatient treatment. I also harbour concerns regarding the practices of involuntary commitment, mechanical restraint, forced medication and ECT. In addition, I remain unconvinced that a strictly bio-medical interpretation of mental illness is capable of catching all the nuances of patients' distress and, when I was able to do so, I chose the nurture side of the nature-nurture debate as the most hospitable location for my own professional practice. Second, as a student of the history of mental illness, I have drawn my understandings from sources whose *raison d'être* is social criticism, regardless of whether or not the author's lens is historical, sociological, anthropological or feminist. These resources have shaped my thinking as a psychotherapist and as a researcher. They have also led me to a third area of research bias, my supportive views regarding the potentially positive role of the consumer and psychiatric survivor movement in clients' and ex-patients' lives.

As a final remark regarding my own subjectivity, it is important to highlight specifically the fact that I came to my role as a mental health professional as a second career, so to speak. As a result, I began my graduate education later in life than is typical and I find myself identifying less completely with my professional status than might otherwise have been the case. In addition, and perhaps because of this sense of separateness, I have tended to question many of the usually taken-for-granted assumptions that underlie my professional role, especially as they relate to mental health and psychiatry. Further, I am neither a consumer nor a survivor and thus, stand apart from this group as well. While having no real place in the mental health field where I can say that I truly belong has some emotional drawbacks, intellectually, it offers me a unique location from which to conduct sociological inquiry in my chosen topic area.

In providing an understanding of my own perspectives and biases, I hope to avoid two problems that can plague qualitative researchers in general, but which are of significant concern in the present work. The first problem is that of over-identification where researchers unwittingly appropriate their respondents' value system as their own. In this situation, the research product starts to resemble a sales pitch for respondents' opinions or causes. The second problem occurs when researchers under-identify with their respondents and impose their own value system (Lincoln & Guba, 1985). Striking a balance between these two extremes can be difficult because, as Waltzer (as quoted in Rosaldo, 1994) notes, "social critics should be meaningfully connected with, rather than utterly detached from, the group under critique" (p. 179). The reality is that all researchers live in a plurality of communities. In my present work as a psychotherapist and as the director of a community mental health agency, I am a part of the mental health community but apart from both the main body of professionals employed in the mental health system and from the consumer and psychiatric survivor movement. In these circumstances, the likelihood of falling prey to either over- or under-identification is mitigated by exposing my own beliefs and values as I have done here and in Chapter 1, then attempting to take them into account wherever applicable (Drew, 1989).

Sample selection

Twenty-two people were approached and asked to participate in the research. As is typical of qualitative research, the size of the sample is of less concern than its depth, which is defined as the importance of working longer and more intensely with a few people rather than interviewing many in a brief and superficial manner. The sample is not intended to represent the rest of the world but, instead, provide an opportunity to understand specifically the life-worlds of only this study's respondents (McCracken, 1990). In this specific case, I was seeking self-avowed *consumers* and *psychiatric survivors,* a group of people that I see as part of, but not equal to the more general category of *mental patients* or *ex-mental patients*.

A concern related to sampling is that of access – how the researcher contacts her respondents and gains their cooperation (McCracken, 1990). In the case of the present work, access was less problematic than it might have been because I knew of some of the respondents through my work. Nevertheless, I was aware that many consumers and psychiatric survivors feel that they have been "studied to death" in clinical contexts and resent yet another researcher taking up their time. Thus, I employed the snowball method of recruiting with many respondents offering one or two additional names of people which they thought might be interested in participating. An advantage of this technique was that I was able to introduce myself to many informants by stating that a previous interviewee had suggested that I call. I found that this form of introduction, aside from simply being a polite way of entering the consumer and survivor network, lent both me and my work credibility. It is important to note that I did not employ any specific method that dictated which recommendations I pursued and which I did not. In fact, most of the names I received led me to willing participants, with only one suggestion proving herself to be completely unreachable by phone.

I employed no other selection criteria than that the respondents in question identified as consumers or survivors and that they were currently active in what is being termed the "movement." I did, however, ask that people be willing to speak to "big picture" issues as well as individual experiences so that I would be able to discuss a spectrum of topics and concerns. In other words, I wanted our discussions to range from the personal to the political.

Thus, all respondents were chosen from among users or former users of mental health services who have developed a profile within the Ontario mental health system through their acknowledged identity as consumers and psychiatric survivors. They sit on Boards of Directors, various committees, government work groups and special task forces. Some lecture at universities and colleges or are employed in projects specifically run by and for consumers and survivors which are funded through the Ministry-sponsored Consumer/Survivor Development Initiative (CSDI). Additionally, they are among the informal leadership that has spontaneously developed in what is being called the consumer and psychiatric survivor movement. As a result, each is well versed in the issues surrounding the present period of mental health reform and in the many other challenges that face their group. All hold strong opinions and voice them with passion and eloquence, albeit with varying degrees of intensity.

My sampling technique serendipitously delivered a reasonable selection of men and women consumers and survivors (6 men and 13 women) but I had to actively recruit people from areas of the province other than Toronto in service of providing a rural or small town perspective versus a large urban one. Seven of the interviewees are from outside the city.

Eventually, 20 out of 22 respondents were interviewed. Two simply did not return my phone call so I was unable even to offer an invitation to participate. A third withdrew permission to use her interview due to involvement in child custody proceedings where it was felt that even an anonymous presentation of her experiences would jeopardize her case. As a result, the textual data includes 19 interviews contained in approximately 300 pages of single spaced transcripts.

It has become more commonplace in the last decade for research subjects to be paid for their contribution. In this case, I was working without a budget and, with one exception, respondents offered their time without remuneration. In the exceptional case, one respondent wove the idea of payment into the interview answers with considerable skill and subtlety. I got the hint and paid up.

A brief introduction of the respondents

The results section of the research contains individual introductions to the respondents but it is useful to have a global picture of the group. One of the common ways of describing the characteristics of a group is simply listing a selection of cultural markers like age, marital and employment status. Thus, out of the 19 respondents, 9 are single, 5 are married or living common law, 1 is separated, and 4 are divorced. They range in age from 32 to 59. Seven were employed through CSDI projects, four in other consumer and survivor initiatives with different sources of funding, 2 were working as direct service providers in the mental health system, 4 were on some form of social assistance and 2 did not work but had private means of support. Three of the respondents had been treated only on an outpatient basis and had not experienced hospitalization.

Basic Statistics

Age	Married or living together	Divorced or separated	Single	Employed	Un-employed	Inpatient	Out-patient only
32-59	5	5	9	13*	6	16	3

**As a brief note, the average level of employment for people with histories of mental illness is between 10 to 15% (Anthony, 1994) while this sample reaches the 68% level.

It was also important to understand the extent of respondents' involvement with the mental health system. Sixteen of the respondents had spent a total of 256.25 months or approximately 21 years as psychiatric inpatients. Lengths of admission ranged from 2 weeks to 5 years with 16 months as the average length of stay and 10 1/2 months as the mean. Two respondents had spent less than a month in hospital, 5 had spent from 1 to 6 months, 1 from 6 months to a year, 5 from 1 to 2 years, 2 from 2 to 3 years, and one had spent a total of 5 years in hospital.

Length of inpatient experience (16 respondents)

Total	Range	Average	Mean
12 years	2 wks - 5 yrs	16 months	10 1/2 months

In addition, I asked respondents about their psychiatric diagnoses. Three respondents said that they had had so many diagnoses that they didn't know what the final verdict was, 1 didn't complete that portion of the questionnaire, 7 listed their multiple diagnoses which included borderline personality disorder, depression and schizophrenia, 2 were diagnosed with manic-depression, 4 with depression alone, 1 with schizophrenia and 1 with a form of dissociative disorder.

Psychiatric diagnoses

Multiple diagnoses	Manic-depression	Depression	Schizophrenia	Dissociative Disorder	Didn't know or didn't say
7	2	4	1	1	4

Data collection techniques and sources

The primary source of data is 19 in-depth interviews lasting from 1 to 2 hours and conducted over a 2 year period. I taped all interviews and then transcribed them producing written texts for analysis. The interview setting was in the location of the respondent's choice; at my office, at their office or home, at a coffee shop or bar. In the case of out-of-town interviewees, I spoke with respondents over the telephone using a special recording device. The main concern was that people felt at ease and not under any time pressure. To that end, some respondents asked to see the questions in advance so that they might think over their answers while others made no such request. In addition, when conducting face-to-face interviews, I always had a copy of the interview questions available for respondents to refer to as the interview progressed. Although this courtesy is a relatively small gesture, through my role as a therapist, this group of people have made it clear that they distrust pieces of paper in the hands of mental health professionals because they have so often been assured that documents such as commitment forms, court assessments, child custody papers and so on were innocuous only to find out that, in fact, they had life shattering consequences.

I employed a semi-structured interview guide which listed 12 - 13 questions, some of which were revised or added in light of the data produced as the study progressed. For example, I used the first set of questions for 3 interviews, revised them slightly for 6 more interviews and then revised them once again for the final 10 interviews. Some of the revisions were simply a refinement so that it was abundantly clear what I was asking. As the results section of my work demonstrate, other questions had to be dropped because respondents considered them irrelevant to their experience. And finally, a few questions were added because respondents raised a number of important topics that I had not anticipated. (See Appendix I for the 3 versions of the questionnaire.)

In addition to 19 interviews, I collected consumer and survivor writings which were published in a variety of forms (newsletters, books, videos, papers, letters to the editor and so on). I also "surfed the Net" for survivor-designed Web pages which, as Toffler (1990) would predict, are becoming ever more prevalent These further sources of information are adjunctive to the main body of data and are useful for providing background and depth to the respondents' comments.

I also kept a journal throughout the research process where I recorded my thoughts regarding the literature I was reviewing as context for the research, the theoretical perspectives which I felt were applicable, as well as my reactions to the ideas brought out by the various interviews. The journal is a record of my efforts to make sense of what I was reading and hearing and, as such, forms an extremely rough, unorganized and unpolished version of the study as a whole.

Interviewing issues and concerns

This research offered some particular interviewing challenges, not the least of which was my own subjectivity. Having worked in the mental health field for twelve years, I knew many of my respondents in connection with my working life and the situations in which we had interacted were varied. I knew two of them as former clients who had long since gone on to other aspects of their lives. Many I knew as colleagues with whom I had shared membership on a Task Force or committee. Some I had not met but knew of through "the grape vine."

From the perspective of research methodology, the most important concern was interviewer bias. My philosophical and political views, which are often judged to be at least broadly compatible with those of consumers and survivors, are well known among most of my own colleagues and by many consumers and psychiatric survivors as well. In fact, this knowledge was one of the strongest tools I had for gaining entry into my field of study in that I was known to share many of the values of the movement as a whole.

The debate in the literature regarding interviewer bias has some interesting things to say regarding interviewing techniques. First, there is the perspective that interviewing must be completely non-directive (Brenner, 1981). May (1991) adds that even subtle language alterations and variance in the interview can exert topic control. The paramount concern is that the researcher, having made up her mind to one degree or another as to what answers she's expecting from her respondents, influences the interviewees so that the needed replies are forthcoming. Fortunately, the semi-structured interview offers both the interviewer and the interviewee a wider latitude than these strictly controlled options. For example, Cunningham-Burley (1985) suggests that the interviewer must conform to standard conversational practice and expect the data that results from the interview to be a joint production of interviewer and respondent. Lincoln and Guba (1985) and Taylor and Bogdan (1984) identify in-depth interviews as resembling conversations between peers and finally, Drew (1989) defines good research as not attempting to eliminate the researcher's personal involvement but, instead, suggests treating it as data to be analyzed. Feminist methodologists also tend to prefer the semi-structured interview because it offers the freedom to develop a sense of connectedness with the respondent while directing inquiry in a purposeful manner (Reinharz, 1992). Finally, Walker (1985) offers some interviewing words of wisdom which are paraphrased as follows: There is no such thing as pre-suppositionless research. There cannot be definitive rules about the use of open-ended questions, leading and loaded questions or disagreement with respondents. Such choices must depend on the understanding researchers have of the person they are with and the kind of relationship they wish to develop in the encounter.

The literature on interviewing methodologies is clear that no researcher can be expected to be bias-free. Instead, the key is to demonstrate an awareness of bias, discuss how it was handled in data collection and how it ultimately limits the research product (Patton, 1990). In the case of the present study, my known biases offered me advantages I might not otherwise have had. In addition, it has been my professional experience that creating a rapport when interviewing consumers or psychiatric survivors demands an attitude of authenticity which, in the case of my research role, translated to a clear statement of what I wanted to know and what I intended to do with the information and opinions once they were collected. When respondents were satisfied that I had honestly stated my business, a trust developed between us that allowed for a more vigorous exchange than would be typical of an interview conducted between complete strangers. For example, I was able to disagree with respondents on occasion because my disagreement, offered within the context of my stated biases, was interpreted as an authentic reach for deeper understanding rather than an attempt to silence debate or impose my own views. Additionally, I was able to probe deeply and query openly what I viewed to be inconsistencies in the spirit of friendly rather than confrontational debate. It must also be noted that my respondents were by no means reticent about offering opinions, engaging in debate or disagreeing vigorously. In short, they impressed me as people who say what they mean and mean what they say.

The tone and quality of the interviews that resulted were influenced by both who I am, as an interviewer, and who my respondents are, as people. For example, my respondents, aware that I was familiar with the mental health system and with their views, dispensed with pausing to define terms and abbreviations with the knowledge that I understood "insider" language and needed no such assistance in order to keep up with what they were saying. In addition, most took an absolutely no-holds-barred stance with respect to offering their opinions on the conduct of my professional colleagues, hospitals and institutions, my own and other community agencies, or Ministry bureaucrats. In the vernacular, they called a spade a spade. Further, most were accomplished advocates who had wrestled often and thoroughly with many of the things I wanted to discuss. They tended to get directly to the point of each question and then moved deeper into the topic, reaching for new meanings and understandings. A few, particularly those I was meeting for the first time, delivered a kind of "set speech" in answer to certain questions, making it clear that they had said these things many times before. Once satisfied that I had acquired at least the basics of their political views, they relaxed into a more informal mode of exchange. However, not all interview questions evoked the

"I've said it before and I'll say it again" response. The question which sought their views on whether or not they had formed a social movement of their own seemed mostly to be a new idea and required some wrestling with before an answer was forthcoming. Also, "what do you think mental illness is? was generally followed by a long pause. Answers came slowly, forming only after a number of false starts and the tentative introduction, "that's a *good* question." Finally, the question which asked whether or not they saw themselves as the government's partners was generally answered with one-syllable swiftness. "No."

Reliability and validity issues

Reliability is the extent to which a particular research method is thought to provide the same answer whenever it is employed. Validity refers to whether or not the method gives an answer which is considered accurate (Kirk and Miller, 1986). Generally speaking, reliability concerns are satisfied in qualitative research by collecting data over time, having independent investigators review the data and reach the same or similar conclusions and by checking with the respondents to see if the researcher has developed an understanding of their life worlds (Brink, 1991) In the present work, the 19 interviews were conducted and analyzed by a single investigator over a two year period. However, the thematic analysis and resulting interpretations were shared as often as my personal, professional and research network would bear. Additionally, once transcribed, the text of all interviews were returned to the respondents so that they could correct errors, expand in written form on points they felt were inadequately covered, or delete material if, upon sober second thought, they believed that they had said something they wished they had not.

Validity concerns are usually satisfied through the use of multiple methods of collection or different sources of data, typically called triangulation (Brink, 1991). Thus, in addition to the texts created by the in-depth interviews, consumer and survivor writings, newsletters and speeches, and my own personal journal, I have the benefit of having worked among my respondents for twelve years. It is important to note, however, that these methods relate only to internal validity -- the credibility of the findings (Lincoln and Guba, 1985). In qualitative research, external validity -- the transferability or generalizability of the results to other times or situations -- ultimately rests with the readers and users of the research product. In other words, an entire community of people will become the final arbiters of the legitimacy of the knowledge produced by the present work (Atkinson & Heath,1991).

Data analysis

The first question in the data analysis process which is always important but which is particularly so in the context of this study, is when does the researcher, herself, begin to own the data in preparation for placing her stamp on the research product? In qualitative research, there is a continuum along which this decision may rest. For example, Lincoln & Guba (1985) describe naturalistic inquiry as demanding a system of what they call member checking whereby research respondents are intimately involved in the entire research process, commenting upon, verifying and altering the researcher's interpretations until the final product can be said to have been mutually constructed from beginning to end. On the other hand, Estroff (Sept, 1995) feels no such compunction and, instead, believes that the researcher has her own unique contribution to make and must be prepared to assert her command over the data as soon as it has been collected. I, myself, chose a position that is close, but not exactly the same as Estroff's. Given the nature of my respondents, I felt it extremely important to the trust-building process that I return transcribed interviews to them for verification because consumers and survivors often describe experiences where they feel that their words and experiences have been appropriated for professional gain. However, once respondents were satisfied that the transcribed interviews accurately reflected their views, in every detail, and they had offered me signed permission to use their words, I felt that from then on, I "owned" the data. As a result, the data analysis techniques and the interpretations that result are my productions and thus, my responsibility.

The analysis of qualitative data is a step-by-step process involving a ever-deepening understanding of the developing concepts (Taylor and Bogdan, 1984). The first step is to read and re-read the data to ensure complete familiarity. In the case of the present study, I transcribed the interviews myself which gave me a second opportunity to re-experience each one, a helpful, although time-consuming option, which allowed for an increased understanding of the data. In fact, hearing, but not seeing, as it were, each interview allowed me to concentrate on tone and I was surprised at the power of the emotion in most respondents' voices which had been more muted in the actual interview when I was distracted by such sight cues as body language and facial expression.

I chose not to employ a computer program which codes the textual data line by line. Instead, I relied on a manual method, the first step of which was to sort the text by answers to the semi-structured interview questions, devising memos which were, in essence, topic inventories from which categories or themes began to emerge. As familiarity with the data progressed, I began to settle on five categories, each of which constitutes a chapter in the results section of the present work. I then re-read the entire data set using only these categories or themes as coding tools. I marked each line or set of lines with a marker pen, the colour of which corresponded to one of the five categories. I found it extremely helpful to be able to visually locate my themes in each interview. The colors pointed out whether or not the themes remained consistent over all 19 interviews. I was also able to see if one or more interviews concentrated on a few themes to the exclusion of others, or if blocks of text within an interview could not be fitted into a theme. These kinds of visual cues allowed me to refine my category titles until all five began to capture most of the data in the majority of the interviews. Closure of this part of the data analysis was achieved when the categories seemed saturated, meaning that the respondents were saying the same or similar things over and over again (Patton, 1990; Lincoln and Guba, 1985).

Also, during this process, I checked each category for internal homogeneity looking for contradictions or negative instances – examples of when the theme did not hold true. When contradictions were found, the theme had to be refined even further, often involving a more accurate category title so that it more closely fit the data set. I also re-read my other sources of data in the service of external heterogeneity – independent knowledge of the consistency of my categories as compared with other examples of consumer and survivors writings, my own journal and so on. At this point, data analysis began to near completion. The five categories were remaining stable and I felt I had the basis for describing the life-worlds of my respondents. It should be noted, however, that it is the essence of qualitative data analysis to look for similarities in respondents' answers while considering dissimilarity to be the exception. As a result, it is a common criticism to point out the not *everyone* could have said the same thing or held the same opinion. Indeed, this is true. Qualitative research results require only that *enough* respondents say the same or similar things to produce a theme (Lincoln & Guba, 1985). Consequently, an inherent limitation of these methods is that they do not, nor are they intended, to produce universal truths.

The final data analysis step was to develop a story line whereby I started to attach inter-related meanings to what I had learned. During this step, I began truly to "own" the data, making sense of it with the aid of my own subjective experiences and the theoretical context I had chosen for the study. It was at this point that I chose quotations which would illustrate the "story" with exemplars and paradigm cases. Exemplars are powerful instances of meaning which readers can relate to their own experience, even if the context is very different than that of the respondent (Leonard, 1989, p. 54). Paradigm cases, on the other hand, are patterns of meaning which describe how an individual respondent has derived his or her own view of a particular situation (Benner, 1985).

In this final step, it is my contention that it is important to report enough of the raw data in the results section of the work so that readers can enter the equation with their own judgments as to whether or not the researcher appears to have developed a credible understanding of her topic area. It is at this point that the reader becomes an integral part of the research act, transcending the individual nature of the researcher's findings which are ultimately constrained by personal values, emotions, opinions and life experience.

Ethical concerns

Permission to use the data was requested prior to each interview with the exception of those conducted over the phone (See Appendix II). In the case of face-to-face interviews, a few respondents elected to with-hold permission until they had seen and corrected their transcript. In these cases and in the case of phone interviews, release forms were sent with copies of the verbatim transcripts to be returned along with the altered transcripts. Many respondents were satisfied with the content of their interviews with some choosing only to expand and clarify some of their answers. However, almost all respondents asked that any quotes I chose from their transcript be altered to reflect good grammar, full sentences and a logical flow of ideas. Given that the interviews had been transcribed verbatim, capturing every word that was said, respondents, many of whom are seasoned public speakers or published writers, were shocked at how verbal conversations "sounded" when they were read. They found the common currency of energetic conversation, examples of which are run-on sentences, inverted logic, incorrect verb tenses, missing words (where gestures had stood in), repetitions, ubiquitous statements of "you know" and verbal ticks like "uhmmmm," not at all in keeping with the standard of communication to which they aspired. Thus, in deference to their clear, specific and multiple requests, I have altered the quotations that I use for conciseness, flow, readability and grammar -- but not for content or meaning.

When respondents signed their release forms which allowed me to use their views and opinions, they had the option of being identified by their full name, their first name only or a pseudonym. Fifteen of the 19 interviewees asked to be identified by their full name, 1 by her first name only, and 3 asked that their identity be concealed. Of these latter 3, one remarked that he had been misquoted and misinterpreted often enough to have become wary of using his real name and requested a pseudonym instead. A second wished to be identified by an initial only to protect her family as she felt she had spoken very candidly. A third respondent asked not to be identified in any way because of the potential for criticism from fellow consumers and survivors and, although the presentation of data calls for some sort of way to identify this contribution as separate from the others, I have honored the spirit of the request by altering small but powerful identity markers which do not obscure the meaning of what was said but do protect the anonymity of the respondent as much as possible. It should be noted that complete anonymity can never be assured as favourite expressions or idiosyncratic word usage may give clues to identity.

The purpose of offering respondents the option to be fully identified relates to two issues. First, I felt that their contribution to the final research product warranted at least the choice of full recognition. The ideas and analyses offered by this group of people have historically been appropriated for professional use with anonymity as the justification. Therefore, full recognition constitutes a political act signally, at least an attempt to create a different research relationship. Second, the nature of the study and the types of questions that I asked were not designed to elicit deeply private material and instead, focused on thoughts that were of a more public nature. As it turned out, respondents often offered very personal stories in order to make their points and give depth to their ideas but even in these instances, most chose to be fully identified. One reason for this openness is that, in their role as advocates, most respondents have presented their personal stories to the public repeatedly at meetings, in legislative hearings or even on radio and television. As a consequence, they see their stories as forms of public testimony and as sources of pride that merit full ownership.

As an additional ethical concern, respondents openly named individual agencies, family members, psychiatrists, other mental health professionals, bureaucrats, their peers and others, regularly stating their forthright opinions both positive and negative. Some of the places and organizations discussed are innocuous references designed to provide orienting information only. In these cases, disguising the subject of the conversation would serve only to render the quoted passages meaningless. However, some descriptions are allegations of misconduct and abuse while others are personal views on specific people or organizations. While the study's respondents are free to speak their minds as they choose, I, as a researcher, have no such freedom. Openly naming this set of third party references would be irresponsible in some cases while, in others, it would be libelous. One course of action that I could have taken would have been to revise the respondent pool for the study and seek out these third parties for interview as a check and balance against what was being said. I rejected this path as it would have diverted me almost completely from the stated purpose of the research toward the new and un-sociological direction of researcher-as-journalist, tracking down sources and verifying statements. The essence of qualitative research is to focus on the meaning respondents' take from a situation, not on the "truth" of the situation itself. Consequently, I decided to respect respondents' views of certain situations by reporting them fully while, at the same time, protecting the anonymity of third parties through the use of general category references.

In conclusion

The advantage of qualitative research methods is their potential to develop new power relationships between researchers and respondents. Certainly, respondents have an increased profile in qualitative research and are accorded a greater measure of control over the final research product than when participating as anonymous subjects in traditional quantitative studies. In addition, the researcher, herself, must come out from behind her data and reveal her own stake in the research act. Finally, Wolcott (1994) cautions against lofty interpretations which leave the data far behind in favour of an effervescent haze of inaccurate insight. Instead, he reminds qualitative researchers that interpretation is the "arrogant work" of knowledge production (p. 258) and that tidy endings offering one-size-fits-all solutions are hollow temptations which, if indulged in, betray the trust of respondents and readers alike. On the other hand, qualitative methods do not ensure "truth" any more than any other research approach. Respondents can talk but they may not answer the research questions (Wolcott, 1994). Further, the qualitative promise of benign intent must be balanced against the intruding reality that it is the researcher who has the fullest control over the final product and she would indeed be less than forthright if she did not admit to putting it to use for the aggrandizement of her own academic career or, in this specific case, for the acquisition of the supreme legitimizing credential (at least to me) known as a Ph. D. In the end, however, it is both respondents and readers who retain the power to judge whether or not the researcher and her product are credible.

CHAPTER 6

A SPECIAL BOND

Mental patients and ex-mental patients are a diverse group of people. Among them, they represent all the variations that are characteristic of the whole population of Ontario. Yet, they are finding their way to one another, forming small groups in their respective communities and then attempting to merge these groups into a larger collectivity. When they meet, they recognize "some common basis of life" (Simmel in Levin, 1971, p. 11) which makes them, at one and the same time, similar to one another and different from other categories of people. They say they have a "bond" which is unique and not shared with any other group (Oswin, in OPSAnews #1, 1990, p. 6). In Simmel's terms, they impose upon one another a veil of mutuality that obscures individual differences and creates a sense of fusion. In other words, they are attempting to meld their seemingly individual voices into a shared cry of protest (Janeway, 1980).

In this chapter, I explore the nature of the bond that members of this group say they share. I ask from what source does it spring and how was it created? I also talk about how this bond leads to the feeling that "you are not alone" and, through the process of what hooks (1989) calls, beginning on the inside and moving to the outside, how ex-mental patients arrive at the place where they feel they have to take action and "do something about it." While the proximate backdrop for this study is the present period of mental health reform in Ontario, respondents did not in any way confine themselves within these specific boundaries. Instead, they spoke about a broad range of subjects, sampling from whatever time and context they felt best conveyed their story. Indeed, stories were the typical answer to the first research question; how have ex-mental patients come to re-define themselves as political activists, as consumers and psychiatric survivors.

Telling stories

In my research, the specific question which turned out to be an entree into this topic was, "What forces led to your original involvement in the psychiatric system? What did you expect and what did you get?" I originally formulated the question as a way of talking about the types of life problems and difficulties that precipitate admissions to psychiatric hospitals. My own experience had been that there seemed to be no single route patients followed which led inevitably to the doors of a hospital. Instead, a series of factors, many which appeared external to the person, seemed to pile one upon the other, culminating in some sort of behavioral outburst that the individuals, themselves, the police, family or neighbours thought best defined in psychiatric terms.

In the interviews, I usually followed this question with a prompt intended to emphasize that I was asking about the *forces* respondents thought led to psychiatric hospital admissions which they may, or may not wish to illustrate with personal information. From my own past experience, I understood that events that precipitate admissions to psychiatric hospitals are often embarrassing or painful to recall. Thus, I wanted respondents to be free to focus on the "big picture" if they wished, instead of feeling cornered into revealing private material that they would rather leave undisclosed.

The second part of the question was designed to get a sense of what expectations respondents had when they asked for help from the mental health system (usually a psychiatric facility). I also wanted to know whether or not they felt these expectations had been met. Obviously, I harbored an a priori opinion developed as a result of my experience as an inpatient psychiatric social worker. I believed that, as professionals, we'd promised a lot but failed to deliver and, frankly, I did not expect to hear accounts of customer satisfaction. Thus, the underlying purpose of this question was to develop a catalogue of respondent-defined life difficulties that led to a request for help, accompanied by a corresponding set of assessments as to why help was not forthcoming.

Respondents answered the questions, not with an objective, intellectualized discussion of precipitating forces or an inventory of complaints -- the "big picture" I was expecting -- but with intensely personal stories that, in essence, were their version of their own history. In other words, they began to provide the answer to the first question posed by this research, by what process had they come to re-constitute their identities? Of course, the whole of each interview was a "story" in the broadest sense of the word, but these questions elicited a unique kind of story-within-a-story which was typically lengthy, told without pause and with great passion. It tended to proceed in sequence, with a beginning, middle and end. Kohler Riessman (1993) speaks of narrative styles where tellers "pour their ordinary lives into archetypal forms" (p. 19). If this is the case, then these are odysseys where struggling heroes embark on dangerous journeys through inhospitable lands, encountering villains and adversities along the way before eventually arriving at their destination, wiser, but also sadder because they have learned a hard lesson and paid a heavy price. These stories are historical in the sense that they speak of real people and report actual events but they must be understood, not as objective facts, but as representations of them. McGuire (1990) states that such historical representations are inherently rhetorical, meant to persuade and inform. Finally, I had the sense that many of these stories had been told before, not just internally as a form of meditative dialogue, but publicly, with an audience to reflect back responses that alerted the teller to the rough spots which were then smoothed away in the next telling, until the story shone forth as a version of personal truth.

Consumers and survivors have been the objects of psychiatric history for well over two hundred years, their lives and experiences appropriated and defined by supposedly well-intentioned others. However, Flack (as quoted in Gamson, 1991, p. 47) argues that "people are capable of and ought to be making their own history." Personal histories are "made" through story telling where people re-connect themselves to their own account of the past so that present life becomes intelligible (Gersie & King, 1990). Friere (1970) states that it is important to "name the world" (p. 80) by placing one's own reality on life events. According to Malhotra Bentz (1989), this reality can be even more important than the event itself. The pursuit of objective truth, at least in the scientific sense, is beside the point. The "truth" of narratives cannot be proved. Instead, story tellers seek a representation of reality which is intimately connected to the listener and bounded by the interpretive dialectic they create together (The Personal Narratives Group as cited in Kohler Riessman, 1993). Respondents' stories represent a metaphorical liberation as the authors re-appropriate what Gadacz (1994) calls their colonized life-worlds. Janeway

(1980) adds that it is the prerogative of the less powerful to reject how the powerful have defined them and begin to develop their own identities which are given substance and verisimilitude through the repeated telling of stories, until both private and public expressions of the present self are recognized as congruent with past experiences and predictive of fresh, future-oriented identities.

The following four stories are examples of recovered histories which form platforms for the development of new identities (Polkinghorne, 1988). I selected these four because the story tellers (three women and a man) are clearly very different people but each eventually shares a similar fate -- they end up on a psychiatric ward. While, as a researcher, I was interested in how they got there, respondents, on the other hand, seemed much more concerned about how they got out.

While I could have chosen to break up the stories into their components or themes, hoping for a deeper understanding of experience through partialization, in the end, I decided that to do so would have done violence to their intended meaning. They represent an indivisible *gestalt* of experience which requires an intact telling from beginning to end so that their similarities and differences are allowed to emerge organically from the narrative context -- as the teller intended.

Four stories

Susan Marshall lives in Fort Francis, a small town some distance from Thunder Bay in the northwest quadrant of the province. She has three children from her two marriages. She is presently divorced from her second husband and has her youngest daughter living with her. Susan is in her late thirties and is employed as the coordinator of a Consumer/Survivor Development Initiative self help project located in her area.

> I was brought up in a home where the message was that we were strong people and mental illness -- I don't even know that I heard the word as I was growing up -- but it was definitely a "no, no" and if anybody suffered from any kind of problem like that, they were less than the rest of us, that's for sure. So when I started having problems, I didn't even recognize what was happening. I just knew that I was "less than" and I had to hide that. So I ended up making my problems way worse than they ever had to be because I hid them for years and years. You know, sometimes, I didn't come out of the house for six months.
>
> At one point, I moved to a city in Saskatchewan where I got involved with the women's movement. Somebody suggested that I go to this "nice" person that they went to for help. Well, I didn't realize what a psychiatrist was to begin with. Not at all. I didn't even realize the wide, sweeping powers they have or anything else. I was totally ignorant.
>
> So, I ended up going to this psychiatrist and she *was* a really nice lady and I think, maybe, I was a bit lucky in that regard. She diagnosed me as manic-depressive. That was like a real "Oh my God!" kind of thing. I was put on lithium and it just wasn't working. And then she suggested that I go into hospital for a few days so they could monitor the medication. So I said, "Sure, that's OK." No big deal. I was just too dumb to know.
>
> So I ended up trying to get off the ward at night -- just innocently trying to leave. And they wouldn't let me. They wouldn't let me go and I got hysterical, which I now recognize was a completely normal response. Then things got really out of hand and I ended up being tied down. I was committed involuntarily for a few weeks and as soon as I could..... Basically what I did was I learned very quickly to play the game and I hid everything that was going on and gave the answers that were expected. Thank God, I'm intelligent enough, you know, to realize these things and I disappeared as soon as I could. Got off the ward and disappeared. And stayed back in the closet for a long, long time, too afraid to go that route again.

Jennifer Reid was thirty-three years old when she told me her story. I met with her at her "suite" of offices which she jokingly calls the small, slightly seedy fourth floor walk-up location of her survivor-run drop-in program where she is the director. She describes herself as a lesbian, part black and part Native, but all feminist. Adopted by a white middle class family as an infant, Jennifer felt that she never really belonged -- "there were no roots for me." She says she's been fighting the "system" for over fifteen years.

I hadn't met Jennifer before the interview and she was cordial but a little wary. She seemed to tell her story as a way of setting me straight about where she was coming from. She started by announcing her "bullshit" diagnosis -- Jennifer says that psychiatrists call her a sociopath.

> I'm an incest survivor. And when I was 19 years old, I ran into a guy who reminded me of the man who abused me and I hit him. The problem was that I didn't stop hitting him and I ended up going to prison for six years. Well, nine, but shit happens.
>
> I went into the Kingston Prison for Women and they have a case management worker who assesses you and figures out where you should go. At the time, I was having flash backs from the abuse and I was very angry. I was upset because the traditional agencies, from the time I was sixteen to the time I was nineteen when I went to prison, were not LISTENING to me. And I'm talking about agencies in Brampton and hospitals in Peel and in Toronto. And I'm talking about the private school I went to. They blamed it all on a learning disability. And that's not the truth. Part of my behaviour problems might have been because of the learning disability but another part was because of racism, and the major part was because of abuse. So I ended up in prison.
>
> My case management officer saw something was up and that it had to do with abuse so she got a woman from Queens University, J., who was doing her Ph.D. on sexual abuse survivors. J. and I started working on the abuse so that was basically my first contact with a psychologist. In Prison for Women, they had psychiatrists, a male and female, and their answer

to everything was to give you Largactyl (CPZ) which, to me, is bug juice. All it did was dope me up and make me go to sleep. J. worked on the issues.

Eventually, I got out of prison on a full parole but I wasn't stable enough to be out on the street, I realize now. When you're in jail, your meals are made for you, you have a set time to get up, a set time to go to work, go to school, go to sleep. You get locked down. You have a set time to do everything. They don't give you life skills training to handle life on the street and after four years, it was heavy. It was hard to just adjust. So I ended up going back in.

Then I got into a fight with another woman prisoner and the warden put me in segregation. A segregation cell is six feet by three feet. Twenty-four hour fluorescent light, a steel toilet and a steel bed -- locked up for twenty-three and a half hours a day. If you're good, they might let you walk around the yard which they called the "tennis court."

So after months of going absolutely nuts, they gave me a choice on December 19th. They said, "You can either stay in segregation until after Christmas, which is the worst time of year to be locked up, or you can go to a psychiatric hospital. "Now, St. Thomas has got green grass, Jennifer, and you'll have a nice little bed and you'll get to wear your own clothes and you'll get to listen to the music you want to listen to and you'll be able to smoke filtered cigarettes instead of roll-your-owns and you'll be able to walk around and associate with people." So I, being the innocent that I was about mental institutions, said, "OK, fine."

At St. Thomas, they took me up in the elevator and took off my hand cuffs and my leg irons. And as the elevator door closed behind me and I walked down this long hall, I realized I was trapped. I was out of the correctional system and into the mental health system and the two, as far as I'm concerned, are the same.

The staff of St. Thomas consisted of two psychiatrists, one psychologist, a social worker and nurses. Now, some of the nurses were trained but the majority of them weren't trained for psychiatry at all. They left the day-to-day workings of the ward and the groups -- the social therapy side of it to these men who ran the program. These men had killed people. They had raped women. They'd raped little boys. These men raped animals. These were the men that were teaching me how to become a sane person. They were the "teachers" and what that meant was they made you sit on a floor in a room for four hours and not move. And you had to hold up your one finger to ask to go to the bathroom. If the teacher didn't like you, and they didn't like me because I was mouthy and a lesbian, they made you wet yourself.

So I got pissed off, got really angry and they threw me into this room called the "side room" which is just a cell where they tie you down to a mattress. They handcuff your legs. They handcuff your hands and then they strap a sheets across your body. And if you are really "lucky," they give you a shot of Haldol and sometimes they forget to give you the side effect drug which is Cogentin. Well, I got Haldol because I'm a borderline personality disorder, and a sociopath with psychopathic tendencies – that's how they diagnosed me. I was sociopath because I was a lesbian, OK? And psychopath because they decided from my tests that my hostility level was way above. Well, that sort of made sense to me considering I'd been abused and been in a prison. It also said that I was a "traditional overly dependent female" meaning that I was a heterosexual woman who was playing at being a lesbian. And they said that if I went through their treatment, I would come out of St. Thomas, not a sociopath anymore. I would come out as a heterosexual female on her way to getting married and BE CURED! Needless to say, ten years later, I'm still a lesbian and I'm still a sociopath and very proud of it.

St. Thomas was an interesting experience because you learned how to manipulate. I mean, they made me go on strip status – strip status was you had to wear their clothes – because I wouldn't wear a bra. Now, I had no chest at that time so I didn't feel I had to wear a bra. They made me write out, the very first time I got caught without bra, fifty times, "I must wear a bra." Rule number fifty-three. I'll never forget rule number fifty-three because I had to write it out five hundred times after the first fifty. And the men would go behind you and put their hands down your back to see if you were wearing one. Now for an incest survivor or any type of abuse victim, that would trigger something that would give them reasons to keep you in St. Thomas longer and to medicate you and to give you shock treatment. I lasted at St. Thomas for two years and then, one day a friend came in to see me and said, "Jennifer, what the fuck are you doing here? You are NOT nuts."

By that point in time, I was "relating" and relating was a two second kiss at the front door and a two second kiss at the back door with a man. It was to get them off my lesbianism. My "date" was an incest survivor himself and he knew I was a lesbian and he was Native and I'm part Native so we both "related" – they called it relating – having a relationship. You could walk around the yard holding hands and he would pull your chair out for

> you and be a perfect gentleman and everything. And all it was, was manipulation to get them off my back.
>
> Anyways, I started relating and I got enough privileges that I could have a handcuff key.... be on the security team so I could throw somebody else down and tie them to a mattress. I also got a lighter. That meant I didn't have to run around trying to get somebody to light my cigarette. I ended up sitting on their treatment committee which was made up of a staff and other patients and we assessed new patients when they came in and assessed people every single day. I sat on the sanctions committee which was punishment committee. I became an assistant teacher and then a teacher. Hey, teachers got to stay up half an hour longer. So, to me, it was just straight manipulation. Was any of the borderline personality disorder dealt with? No. Was the abuse dealt with? No.
>
> Their idea of dealing with someone was... there was one woman in there who was delusional. Before she came in, she was twenty-seven floors up in her apartment and she threw her baby out of the window because she thought she was sending it to God. At St. Thomas, she would never go near a window and was one of the sicker patients. And we had these intense groups.. it could go on for as long as three days, two hours in, two hours out, two hours in, two hours out. But the person that is the object of the group doesn't get to sleep. They feed them but they don't get to sleep. It's called breaking a person.
>
> Anyway, with this woman, I saw it and that's when I started to rebel. Somebody noticed that she wouldn't go near a window 'cause she threw her baby from a window so they had a group on her by a window. They put up a blanket and held her by the window until they broke her and if anybody thinks,... when you transcribe this and they read this, that I'm not willing to say this to St. Thomas's face, they've got another think coming. I've been saying this about St. Thomas for years -- publicly, in the newspapers, and in videos and on the radio. That's just one case. I mean, for me, it was a little bit easier because I was just an "overly traditional female" -- dependent female at that, and needed just to get away from being a lesbian. And all I did was manipulate. I related with this guy who had some of the same problems I had. We held hands, had our two second kiss and laughed at them and I got out and he got out.

The narrator of the third story is Marilyn Nearing. I interviewed Marilyn by telephone. She lives in Keswick, a small town about one hundred kilometers north of Toronto. Marilyn is in her late forties, married and the mother of a nineteen year old son. Although she was describing painful experiences, the telling of her story was interspersed with delighted and infectious laughter.

> Some years back, I was working for Revenue Canada when my life was threatened by a disgruntled tax-payer. I had been a person who thought that you could control your destiny, mind over matter, and it was the first time in my life that I had ever experienced physical illness and re-occurring headaches. I had maneuvered through life pretty successfully, bowling people over. I had a survival technique that worked for me and that meant shutting out the rest of the world and believing that I could just wish things away.
>
> When I first got ill, I thought it was totally physical -- high blood pressure and migraine headaches that I never had before. I was assured -- I assured myself that I had a brain tumor and that I was either going to die or they were going to operate and it was going to be OK. Eventually I started having flashbacks and re-experiencing childhood sexual abuse. I think I'm probably one of the classic cases of regressed memory. By then, they had got me addicted to pain killers -- *never* self- administered, I might add. I used to get daily shots of Demerol from my doctor. I got so I could walk and move with it and it didn't do anything. I couldn't do without it either. I truly became addicted. So now, I had two problems. By the time that I decided that dying would have been a better option, I was not only suffering severe depression and chronic pain but I was also having flash backs and wondering why I wanted to murder my brother. I had also become virtually bedridden for the better part of two years. Through addiction and mental health problems, I finally realized that these little flash backs had to mean something and I went to a psychiatrist. So far, all that calling this a physical ailment had gotten me was addiction.
>
> So, I was diagnosed with depression. I also managed to go into hospital and come off Demerol which was no easy feat. And while I was institutionalized on the local psychiatric ward, I saw how people were treated. I was just dumb-founded. I couldn't believe it. I had come from an omnipotent position -- the tax-collector and enforcer -- to having no power and authority and I saw people abused even more than I was because, even at my sickest, I was still somewhat in control. I just couldn't believe it, and I had to re-examine my whole belief system about schizophrenics and manic-depressives and clinically depressed people. I mean, I had a

> real revelation. These are people that have problems and who will get well if they get support. I just couldn't believe the cesspool of discrimination that was there.
>
> I then started into therapy about the flash backs. It was a grueling two or three year process identifying the memories, having them validated. Fortunately I got a psychiatrist who wasn't too busy at the time and could take a fair amount of time. I don't know whether his business was growing or he was incapable of dealing with it but he referred me to a group here in York Region and also to a program for abuse issues that they had at the hospital run by an occupational therapist. Those two programs really did a lot of good for me and at least this doctor referred me and didn't sit on it. I have seen women in the system for years and years where they don't get well until the abuse issues have been dealt with. They go through the traditional mental health system, diagnosed and re-diagnosed over and over again and finally someone twigs to the abuse and, like myself, they get better.
>
> Then, of course, everything that happened in my body became psychosomatic instead of physical. I started having flooding... I was having three periods a month. I mean, all I had was periods. I should have taken out shares in Kimberly Clark. It was just horrendous. And I really had difficulty getting to a female gynecologist. But I finally found one and she saw me one day when I was flooding -- just like I had told everybody I did. She said, "You can't live like this." I'd already told three male gynecologists and they'd said to me, "There, there, Mrs. Nearing, it will be all right." I had a hysterectomy and I haven't had a period since. Glory hallelujah! Give me hot flashes any day.
>
> Anyway, I realized that you cross that border one day. At first everything was physical and they would only look at me that way and the next day, it was all psychosomatic and they'd only look at me that way. It's a real struggle to get them to look at you as a whole person, you know, and deal with everything. It's when you're asked to divide yourself up in pieces -- or when they divide you up for you.. it's no wonder we go crazy!

Paul Reeve is the final narrator. At forty-three years old, he is divorced and, at the time of the interview was the coordinator of a consumer- and survivor-run program in Guelph. When I asked how he would like me to describe him, he said that all I needed to say was that "bald is beautiful." Paul's story, perhaps more than any other, emphasized the "pouring" of his life's journey into an "archetypal form" (Kohler Riessman, 1993, p. 19). He also moved beyond the boundaries of his disillusionment with psychiatry and psychiatric hospitals, and offered a description of the alternative forms of help that he eventually found.

> I remember the very first psychiatrist I went to. I'd lost my job and I was devastated. I think it's fairly typical as a male. I took a lot of my identity from my work and I was a workaholic. So, I started moving into what they call a major depression. I call it deep, deep despair. And I had a psychiatrist tell me that I would have done better if I had quit my job, gotten out of my marriage and moved away from my home. And, all I know was, at that time, everything in my body and my head said, "No." That's all I could say. "No, you're wrong." I can't even be sure that I even expressed that to him. I may not even have had the strength. I had expected him to tell me something that would make me be better. But instead, I got a psychiatrist telling me what to do and the other side of the equation was, I didn't get better.
>
> After six months my wife did leave. She said she didn't wish to be around someone who wasn't capable of pulling themselves up by their boot straps and my little hummer went off again.
>
> I call it my hummer. I think the books call it a conscience or something. It hums in me. It's wonderful. If I'm in a situation now, I trust my hummer. I move when my hummer tells me to move, not when my head does.
>
> Anyway, medications were being pushed on me. "Try this medication" and I'd try it and I'd have dry mouth or my stomach would hurt or I wouldn't be able to see very clearly, lots of different body reactions. I just stopped. And they'd keep pushing more and more medication and my hummer would say, "No, no." And then they started calling me names, "You're a resistant patient. You're going to be dead because you're not listening to me. You're going to go out and kill yourself." I was suicidal at the time. It was an option and not seeing any other alternative, the only option.
>
> So I think all of that helped me to eventually work towards trusting my hummer and I did seek out alternatives, almost on an unconscious level. Everything told me that I couldn't heal that way.

My belief is that whatever lessons, whatever positions we are put into in life, we'll keep returning to that until we "get it." So, when I was seventeen years old, I was in a mental institution and twenty-seven years later, bang, right back there and almost in the exactly the same spot and experiencing the same situation. I even lost a girlfriend earlier and this time I lost a wife.

So it was almost as if I had to go back to see what the lessons were that I didn't get -- or hadn't been offered at age twenty. You see, it's hard to learn the lessons you need to as long as the mental health system keeps telling you, "We have the answer... we're going to find the right drug. We're just working on these drugs -- they've got some side effects but we're gonna find the ultimate one ... real soon... we hope."

And what I found -- I'll never forget what I found the first time I walked into a twelve step group when I was in very deep despair. I walked in and somebody just said to me, "I'm really glad you're here. And, we love you. And you don't need to do anything." And that was like, profound, and my whole recovery is based on that. All of a sudden, I got it. "I don't have to do anything and I'm OK." That's like a one hundred and eighty degree shift from going to professionals and hearing them say, "We're just going to try one more medication.. one more therapy. We've got to try this avenue. There's just SOMETHING we got to do in order for you to get better."

And here's a twelve step group, run in a little church basement and nobody had any credentials or anything other than love and acceptance. I just wept through the whole meeting. Nobody had ever said... boy, I get feeling sad.. happiness and sadness right now. Somebody said, "You're OK right where you are, Paul." All of a sudden I began reading again and calling people and reaching out and asking what is this spiritual stuff? There was this whole new world and nobody had told me about it.

So, ultimately, my strength carried me slowly towards something that worked. I went into to a chapel one day, it's called Mount Carmel. It's in Niagara Falls. I have no religious background. I don't go to church. I walked into this chapel and I was so low. Anyway, there was a priest there and I said in all sincerity, "I think I need religion because I'm losing the battle here and I'm losing it quick. I'm going down." And it was a sincere question... or a sincere desire because somehow there was a spark in me that didn't want to die but I didn't have any answer.

> And the priest looked at me and smiled and said, "I think it's the *last* thing in the world you need." And I'm thinking, WHAT? My last little hope. And he said "But if we can find a little bit of spirit in you, maybe we'll have a good start." From there on, he gave me support and encouragement and allowed me to be in the church for many months. I would go everyday and for many weeks, the best I could do was go and sit... sit in the chapel and cry.
>
> I cried for months. All of that was healing. I was just releasing what was frozen inside of me. To this day... why did I walk into that place? It's absurd. At any intellectual level, I just couldn't.... so something inside me does take me where I need to go even when I'm not aware of what it is.
>
> And the next thing I did, well, I ended up on a plane. I called a place on a Thursday and ended up on a plane to Texas the next Tuesday. Again, my hummer said, "Just go." I was still pretty bad and ended up with a wonderful, beautiful lady. She's a psychiatrist. She gives no medication. She is not well liked by her profession, by her peers. And she was able to say to me, "You need your feelings. You have them.. you just need to get in touch with them. " She was connected to her heart. She was able to share her experience, to be a human being with me. I got to see a human being across the desk... well, it wasn't across a desk... it was in a room. It was incredible. That was probably about the seventh psychiatrist I had been to and I finally found hope.

Sadly mistaken

Janeway (1980) believes that both the powerful and the less powerful want their power contract to be a success. "We want to believe that things are going well, that princes can be trusted to act wisely and sages to foresee the future correctly" (p. 164). Clearly, these story tellers are both sad and angry with a psychiatric power contract that they believe let them down. As Supeene (1990) writes, "They'd promised to *help* me (p. 71) and instead, "abuse and oppression is what psychiatry meant by help, care and therapy" (p. 231). Jennifer Reid adds:

> These people are professionals. You would think they would know what they're doing, that they would help me with the abuse, that they would help me with all my issues so I'd get better... be able to go out into society. I believed that they would fix things. That's how I was raised. Well, I was sadly mistaken.

In addition, there is a sense of embarrassment because respondents were, as Susan Marshall says, "just too dumb to know." As a result, they see themselves as especially fortunate because getting out of a psychiatric hospital did not entail the expected path of receiving help and getting better. Instead, it involved a combination of luck and manipulation which respondents define as going along with the rules and telling professionals what they wanted to hear -- "I'm fine" -- when they really felt the same, or worse, as when first admitted.

In the end, a resolution for respondents' problems" -- "issues" as Jennifer Reid calls them -- had to be found somewhere else and good fortune was seen as the companion that guided the journey. Paul Reeve calls it following his "hummer" and many respondents, in the standard colloquial way, thanked God for their good luck.

> Thank God, I'm intelligent enough
>
> God, if I hadn't already been familiar with the Mental Health Act
>
> If I hadn't had the social supports that I had...
>
> I guess I had enough stubbornness, enough stupidity, enough fight ...
>
> I was fortunate because I slipped through the cracks. When they do their assessments, they say I resist authority... don't respect authority, whatever. For me, that's a redeeming feature because I never got sucked in.

McGuire (1990) believes that, in order for narratives to persuade, they must reach beyond content (the facts) and form (an odyssey), and present a moral or lesson. In this case, the hero of the story, with the supposed aid of luck is transformed from unknowing innocent to someone who finally sees the truth -- and in the process pays a price. However, a close reading of each story reveals that considerably more than luck contributed to the transformation. Each teller, in his or her own way, was observant, resourceful, persistent, creative, and, given the nature of their difficulties, I would add, courageous. But, as Janeway has stated, people who believe themselves to be powerless are among the least capable of accurately assessing their own strength. Consequently, these are stories where a positive resolution is attributed only to forces considered outside the teller's control. God and luck, instead of individual power and agency, are the perceived guides for this set of heroes as they make their escape from danger.

In fact, respondents tended to view their exit from a psychiatric hospital or psychiatric treatment as a form of abandonment rather than liberation. Each story teller has reluctantly concluded that psychiatry's promise of help, while initially raising hope, turned out to be as cruelly empty as a desert mirage. Instead of finding the comforting and restorative haven that would end their weary journey, respondents found themselves forced back out onto a lonely road, carrying the added burden of bitter disillusionment. Perhaps, in this sense, the stories are reminiscent of the most famous odyssey of all -- the Biblical "fall" where Adam and Eve, after eating from the tree of knowledge, are banished from the garden and forced to make their way in a dangerous and uncertain world. Thus, in service of the rhetorical purpose of the narrative -- to persuade and inform -- respondents seem to have built their story within a familiar mythical framework which serves to strengthen their connection to their audience and, by extension, their argument (McGuire, 1990). It is not, however, a framework which celebrates triumph and freedom. Instead, it emphasizes desertion and loss.

The stories began with a call for help which respondents believed would be answered within the bounds of the traditional psychiatric power contract. After all, the mental health system promises help and, as Jennifer says, "I believed they would fix things." However, Janeway believes that such faith is akin to believing in "fairy godmothers (and) wise old men." Skepticism and disbelief, she says, are the essential accouterments of adulthood, creating "an autonomous creature centred in an independent self" (p. 165).

Yet, it must be acknowledged that Paul, in particular, described an extensive search for a rescuer, and his persistence finally paid off. Paul was not alone. More than a few respondents reported that they eventually found help within the mental health system and it was provided by a mental health professional.

> J. worked on the issues.
>
> Those two programs really did a lot of good for me.
>
> I ended up with a wonderful, beautiful lady.. she's a psychiatrist..
>
> I found a woman who listened to me.
>
> My shrink sent me to an advocacy program where I became aware of my rights.
>
> I found a male psychiatrist who was very helpful.
>
> I found a community program that made all the difference.
>
> I was seeing a psychiatrist and he was actually very good.

Respondents conclude that these "finds" are also lucky events and in this, Miller (1984) might concur. She argues that liberating power relationships -- those which encourage, teach, nurture and guide -- are not the common basis of our society's child-rearing practices and, as a result, may indeed be rare experiences in adult life. Nevertheless, these seem to be the sorts of relationships respondents hoped for when they entered into the psychiatric power contract. In the face of dashed expectations, they speak of themselves as "sadly mistaken" and "lucky" if they actually got what they wanted. Indeed, having got what they wanted -- finally -- appears to have not erased memory of previous failures. They now know that things can go badly wrong for the innocent. They feel alienated and adrift -- left on their own (Berger, 1977). They can see what others do not, and the process by which that knowledge was acquired was deeply disturbing -- in fact, traumatizing may not be too large a word to describe their view of their experience.

A special bond

Janeway states that powerless people are especially aware of their own vulnerability if power contracts fail because they are the ones most likely to suffer. When things turn out badly, stories are a valued method for making sense out of the trauma. Wigren (1994) states that "the construction of a narrative is a psychological achievement" (p. 415) which first, connects emotion to experience and second, scans the inner and outer life-world in order to develop a causal chain of events that establishes meaning. Finally, it draws conclusions which are intended to create an understanding of what happened.

Stories also form "an essential part of the fabric of social exchange: people relate to each other, indeed construct each other, by sharing stories" (Demattos as cited in Wigren, 1994,p. 416). Mutual understanding, according to Bruner (1995) "assumes social obligations of the most blinding and serious kind" (p. 27). In other words, it creates a special bond. As an example, this brief fifth story serves also to add dimension to respondents' "luck," reiterating its role as a mediating mechanism employed to explain a positive resolution to what was viewed as an enormously painful experience. It demonstrates that it is a shared understanding of the emotional foundation of each story which creates the special bond among one's peers.

The narrator is Susan Hardie who was, for a long time, the coordinator of the National Network for Mental Health, a federally funded consumer and survivor organization. At the time of the interview, she was thirty-three, had just left her position with the National Network and was struggling with plans for her future. This was her answer to my question about what got her involved in the system in the first place

> I asked for help -- I learned afterwards why it felt so horrible because it was just like someone was reading from a text book and they weren't listening to me as a person. I had struggled on my own for three years and then I had asked for help and the person promised help and then didn't follow through. It devastated me as a person. I tried to take my life as a result and I ended up in ICU with my family doctor asking, "What happened?" and I said, "I failed." Somehow, I had lost my spirit -- the spirit that was fighting to stay alive for three years on my own when I was continually suicidal. I guess the thing was that the power of the system, whether with good intentions or not, tried to destroy the little bit of fight that was left in me. When I said I had failed, I knew I was broken. We're not talking about anything that is outside of me -- it's the part that keeps me ticking and it's that part that connects with other consumers and survivors because they know I've been there.

Marg Oswin would support Susan in her views. Marg has a careful, considered way of speaking that belies the passion behind her views. She spoke with me at the offices of an advocacy program where she is a member. Marg is single, in her early fifties and works part-time as an office cleaner for a survivor-run business. She explains further the connection that "having been there" creates.

> I entered a convent when I was eighteen years old. I left five or six years later because I couldn't find peace within myself, and I wanted to feel differently. Again, looking back, I believe this all stems from the abuse I suffered when I was child. Something was wrong but I didn't know what it was and didn't want to think about it. I began to take drugs. I took valium. I took speed. I took anything that would make me feel different. In 1980, I guess it was, I was taking hands full of valium and wine and things like that and, of course, it led to what the doctors call a psychotic episode and I, well, I was dragged into hospital, kicking and screaming. I withdrew from valium cold turkey. I also got diagnosed and mis-diagnosed. I got brain-damaged from ECT. I got lots of different kinds of medication that delayed my taking action against the real problem. So I got twelve or thirteen years of postponing work that should have been done a long time ago and that I've been doing now for four years.
>
> So, I always think of survivors as having a special bond. It's unique -- maybe I shouldn't say special. Because... again I'm just working this out as I go... because the situation that we find ourselves in is that we are treated with electro-shock and with drugs, things that work on the mind. They make us question ourselves and our power and reduce us.. well, I'll speak from my own experience, reduced me to being unsure of my ground. I became a cipher. And it was only through the support of other survivors, and some service providers as well, that I was able to pull myself together and find out that I have strength and power of my own. With survivors.. among ourselves particularly.... because we've faced this kind of oppression.... of the mind and of the spirit -- and we've all experienced it -- it's the sharing of a special kind of emptiness and aloneness and despair -- and hope -- that I haven't seen with other forms of oppression.

While most respondents were adamant that they shared the type of bond that Marg describes, there is a small nuance that merits mention. Respondents who had *not* experienced admission as an inpatient to a psychiatric facility tended to refer to their fellow consumers and survivors as "them" and "they," while those with inpatient histories more typically spoke of "we" and "us." While this is, admittedly, a small point, it adds depth to the idea that some people experience inpatient psychiatric treatment as traumatizing and, therefore, as particularly capable of creating a bond among their peers that has special cohesion.

As a final point, Cassin (1993), herself a psychiatric survivor, believes that the bond which consumers and survivors presently share is based solely on a mutually-acknowledged set of grievances. While she agrees that consumers' and survivors' complaints are many, she warns that "grievances (can) become ends in themselves, rather than problems which must be solved" (p. 176). The danger lies in creating an *esprit de corps* based on a never-ending search for more and more complaints, siphoning off much needed energy which should, more properly, be focused on creating positive change. She goes on to say that movements based exclusively on the shared grievances of their members can find themselves unable to celebrate gains because resolved complaints, instead of signaling success, represent the frightening erosion of solidarity.

The personal becomes political

The stories respondents told are already indicative of a collectively developed "truth" because one of the most important audiences for their telling has been each other. The power of narratives, McGuire (1990) states, lies in their ability to "tell us, as groups, what to believe and why" (p. 225). The few historical examples of patient and ex-patient stories that have survived, were told in isolation from one another; to diaries (Geller and Harris, 1994), to unresponsive doctors (Reaume, 1994) and, in rare circumstances, to a curious public intrigued by glimpses of life in a madhouse (Beers, 1908). These long-ago stories are remarkably similar in content and theme to their contemporary counter-parts. Chamberlin (1978), who has listened to literally hundreds of her fellow ex-patients describe their hospital experiences, states that "it's amazing how the same themes, often the same words, occur again and again.... (Ex-patients say,) 'You tell them what they want to hear. You learn to play the game.' " (p. 68). However, the reality is that these isolated voices have had little overall effect. As one respondent said, "It really frightens me because there isn't even anybody saying this is wrong except one group -- the victims of it -- and nobody is listening to them."

Chamberlin (1978) believes that, if mental patients want real help, they are going to have to provide it themselves because both psychiatry and professionally-developed alternatives have failed. The so-called therapeutic community simply disguised the power of the professional staff who, without a doubt, retained veto power and only permitted patient decisions if they agreed. R. D. Laing never treated his patients as equals, as he claimed, and he only believed what they had to say after he translated their words into his own ideas and concepts. The spread of community mental health programs is especially frightening. "Where once the state found it more convenient to incarcerate us permanently, it now seeks to control us through a network of facilities" (Chamberlin, 1978, p. xii). And finally, feminists are seen as especially traitorous because, as women and as fellow oppressed peoples, they ought to know better. Psychiatric survivors often see feminism as a white, middle class indulgence that has no relation to their every day lives. Capponi, in a 1992 Toronto presentation to a group of feminist mental health service providers, advised that there are two classes of women -- workers and the worked-on -- and in many cases, the workers just don't get it. Women who live in violence and poverty have no time for feminist navel gazing. Keeping themselves fed and their kids out of the Children's Aid is more than a full-time job -- with no guarantees of success. Lectures on the hazards of domestic violence have little meaning when the choice is between life on the streets and a roof over your head. In fact, mental health workers' well-intentioned but thoughtless interference can place women in even more danger. In comparison, professionals go home at night, in cars, to a safe neighborhood and a family. Who are you, Capponi asks, to define our needs and why do you think you can give advice when you have so little understanding of the true nature of our lives? As for feminist therapy, "how does an hour of talk change the fact that incest, rape, battery and harassment are cultural norms?" (Raymond, Lear, Bostick, Bradford, Chamberlin, Price & Dumont, 1982). Capponi's view of therapy is equally clear. Nobody, she says, is going to mess with her head.

In 1971, the Vancouver Mental Patients Association began operation as the first organization completely run by and for "users" of the mental health system. In the United States, the self help movement was delayed somewhat because of a less welcoming funding climate but today, Chamberlin (1990) describes the rise of mutual aid among American consumers and psychiatric survivors as a strikingly successful phenomenon. Ironically, despite a promising beginning, self help in Canada has had a lesser impact. Hardie (as quoted in Everett, 1994) states that the reason for this disparity is one of the down-sides of the Canadian social welfare and health care system; dependency on the part of recipients. In Canada, the establishment of self help can be seen as biting the hand that feeds as well as competing with professional interests. As a consequence, many self help initiatives in Canada have suffered from a strong professional presence, often negating their very purpose (Everett & Shimrat, 1993).

Self help organizations create a welcoming environment for the incubation of collective mistrust. Personal stories, such as those told by this study's respondents, find a sympathetic audience among peers and, as a result, have become the hallmark of the "self help way" (Everett [ed], 1994, p. iv). Gamson (1991) calls these types of mutual aid organizations, movement halfway houses. Self help groups serve to create "an environment in which a collective action consciousness is fostered, personal skills are enhanced, knowledge of earlier struggles is acquired and a vision of a future society is developed" (Gamson, 1991, p. 38). Stories, when told to one's fellows, name the "self as a site for politicization" (hooks, 1989, p. 106) and foster feelings of mutuality and community, nested within a burgeoning sense of political purpose. However, by their very nature, these stories emphasize one main aspect of personhood and concentrate principally on one set of experiences. The process of making the personal political adds social dimensions and implications to these sorts of narrowly focused individual stories, but in a particular way. It makes the "distinction between experiencing a form of exploitation and understanding the particular structure of domination that caused it" (hooks, 1989, p. 108). Thus, politicization is the attempt to move beyond merely a shared understanding of grievances so that a connection with the wider social world can be established, but in a way that is aware of its flaws and of how its structure can wound or even annihilate certain groups of people simply because they are outside the universe of obligation (Gamson, 1995). In the micro sense, a political act "recognizes implicitly the existence of another member of the power relationship" (Janeway, 1980, p. 222). Politicized movement members, in this case consumers and psychiatric survivors, have come to "see" and "know" themselves as social beings embedded in a web of power relationships.

One of the goals of my research is to understand the process by which consumers and survivors connect the personal with the political. Donna, who asked to be identified by her first name only, told her story in response to this question. She is thirty-nine years old, married with one son. We spoke over the phone because she lives about fifty kilometers east of Toronto in what might be called a "bedroom community." However, I had met Donna before because Marilyn Nearing had introduced me to her at a conference.

Donna's father died when she was a baby and, in retrospect, she thinks that her mother slipped into a deep depression and never really got over it. Eventually, Donna, herself, became depressed. "Maybe I just learned how to be depressed or maybe my emotional needs weren't met because I was being cared for by a depressed person." Whatever the case, Donna began seeing psychiatrists as a teenager and refers to them as "poor man's therapists" because their fees are covered by Medicare. Even though Donna had never been hospitalized on a psychiatric ward, she, too, felt betrayed by the failure of the psychiatric power contract. "I expected that I would be told why I was depressed, how to get over it and how to move on with my life. What I got was nothing. I asked questions and I got no answers." Eventually, Donna got a job as the staff member to the Patient Council[1] in a provincial psychiatric hospital. One of the tasks of the Council is to deal with complaints from patients. It was here that she feels the process of politicization began for her.

> I'll tell you, I had an experience in here. We were dealing with a patient and she had quite a lot of valid concerns and complaints so I just went through the normal routine to get them addressed. The things that happened to her.. I mean, she was beaten up. She used to go home and visit her son on weekends and after her complaint, the very first weekend she came back, she had a bag of things with her and they did a search and seizure which they do if they feel you're a threat. She'd been checking out of this ward for a year on weekends and they never searched her once and this day, they searched her stuff and beat her up because she resisted. It was just incredible.
>
> And her psychologist would bring her to tears by reminding her that she was suicidal. I mean, the things that happened to her were so atrocious but many were so subtle that you couldn't make a complaint that was concrete. It was all innuendo and it was insidious what they did. They really tried to destroy this girl because she made a few complaints.
>
> So we talked to her endlessly about dependency on the system, about what the health care providers have to offer and I mean, this was not our political tirade. It was her coming to the realization that they couldn't help her. And they switched her wards and then the talk around the hospital was that they were all waiting for her to attempt suicide so that the Patient Council could get blamed for it. It was just an awful experience.
>
> Finally, this young lady left. She signed herself out of the hospital. We've kept in touch with her. It's been a year and a half now and she's doing very well. I mean, she's not working but she's certainly looking after her son and her husband and she's functioning and doing some advocacy work for people in the community. She has bad days just like everybody

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[1] Patient Councils were created in Ontario's provincial psychiatric hospitals as yet another expression of consumer and psychiatric survivor participation. Money was allocated to hire consumer and survivor staff to facilitate the recruitment of a group composed of, usually, outpatients to act as advisors to administration. Councils have also developed for themselves a kind of watch-dog role, offering a place where inpatients can take complaints.

> does but the point is that if she had believed what they said, I think she would be dead. And she chose to decide that they were not going to help her. She had to struggle through whatever this was herself, with her own methods and her own means. And she did. And she came out on top. I look at her now as a particularly strong individual but if you had seen her at the time, I mean, they had her in tears all the time and she was always upset. And she was always in trouble.
>
> And I'm not blaming it on the health care professionals. I'm simply saying that they're part of this social construct and they're the reinforcing tool. Once you get here, man, they plant these ideas in you for sure. So, for me, watching this little girl who just made a small complaint at the beginning... well, I know now you cannot win. You cannot win, no matter what you do. Except to follow the rules. The more you do what you're told, the more likely you are to get out. You don't get better. You don't learn how to stand up for yourself. You just get out.

While Donna couldn't be clearer about the triggers that led to her politicization, Susan Marshall says that her route was a "long, complicated process."

> At first, I hid. Then, I did the "I'm the only one this has happened to" route -- which, of course, meant that I couldn't do anything about it. As I discovered my peers and I discovered that I wasn't the only one this has happened to.. the more I heard, the angrier I got, that's for sure. So it was sort of the process -- along with deciding what to do about it... deciding actually what was wrong about it or what was *in common* wrong with it.

Sometimes, as Susan Hardie explains, it's just one thing, an experience that sheds light where none existed before. The psychiatric facility in Susan's town is one of the few in Canada that is funded through both private and public means. As a result, the patients, too, are divided; some are public and others are private. She says:

> We are all supposed to be equal. The public beds are supposed to be for those who are most in need but the people are treated *very* differently than those in the private beds. So I signed myself out. My doctor said,

> "Susan, you cannot separate the politics from your own healing.' And, the last day I was there I said, "That's unrealistic." The reality is that that's part of me. My healing is personal but the politics, I just can't help but see the politics.

Jennifer Chambers would agree with Susan. Jennifer, like Donna is employed as staff to the Patient Council at Queen Street Mental Health Centre. She originally trained as a psychologist, completing part of her Masters degree. We met for a drink in a bar near my office and the background noise nearly drowned out her quiet voice. I have occasionally witnessed Jennifer in action in her public role as psychiatric survivor advocate and I have come to the conclusion that the gentleness of her voice is an effective tool for capturing the attention of her listeners so that she can deliver her razor sharp critiques. At thirty-seven, Jennifer is a step-parent which she says is, "a very formal way of describing my relationship to the two teenagers I live with." She also wants it known that her identity as a psychiatric survivor is not her *whole* life.

When Jennifer was a teenager, she attempted suicide after "giving out fairly noisy signals that fell on deaf ears." She was subsequently hospitalized and when she tried to leave, was committed on an involuntary basis. In order to get out, she had to appear before a group of professionals, in the company of her mother, and prove that she was sane -- which, she says, "I'd defy anyone to do." She had hoped that the hospital staff would "help her get what was inside out." However, not long after she was admitted, a ward social worker told her that if she didn't "snap out of it," she would be given electro-convulsive therapy. "I learned quickly to pretend that I was fine which, of course, was the problem in the first place."

However, it's not solely Jennifer's hospitalization experience that led to her political beliefs. Instead, she has credits her present job and her brief experience as a professional with "opening her eyes."

> It's hard to separate my politics from my feelings. I used to have a position that was sort of more empathetic to all sides and I'd say that the work I've done in the last few years has made me angrier... battering my head up against the brick wall of the Ministry of Health and the hospital administration. It's harder to see the humanity of the people I'm dealing with than it used to be because I'm not treated with humanity. In a way, I think it was a relief for me to discover the psychiatric survivor perspective because when I was working as a professional counsellor, there was a discomfort with the sense that I was always kind of putting something over on the other person. It's partly because I had experienced the other side so I'm more sensitive to it. It's very difficult to be natural in either role and they *are* roles. When I started the co-counselling that I do, I found a philosophy that was compatible with my own so that gave me an initial sense of support for my views and eventually the survivor movement provided the political analysis which I think is a power analysis. It was somehow a relief to be able to share with people my experience of being hospitalized, to say, "OK, I'm one of you." I think that if I hadn't started peer counselling, I might have tried to forget my hospital experience but I'd have kept the shame.

Three other respondents spoke of their politicization in this way:

> I was a political woman. I was a feminist. I was involved in a lot of anti-war activities. I had that framework but I didn't have the psychiatric survivor framework. That came after meeting other people that had similar experiences and hearing their stories and hearing about the oppression. It made me very angry and I had this great need to speak out and organize and go to demos and try to change things.

> I think when something is done to you in a very condescending, very deleterious way -- where you lose your place of residence, where you lose your self respect, where you lose a significant other... where your whole being drops to such a level.... You can either fight or you can

> drown. I chose to fight and..... and it, well, it leaves a person wanting to help. Which doesn't mean you come out swinging at everything you see. It just means that you have a healthy cynicism, a healthy need to get involved, to take your lumps. You also have a healthy respect for people in your own situation and a desire to go and look for the people who somehow figure that simply because they have all these degrees, they should be listened to more than other people who haven't. And say to them, "Get off Mount Olympus and get down here."

> Well, I don't consider myself an activist. No, I don't. I just think that I do what needs to be done. Speak up when somebody needs to speak up. There's saying that goes like this: "When good men sit back and do nothing, evil triumphs." And I'm a full believer.. a *total* believer in that because I feel that if I can contribute to the system, to society, then a lot of injustices will be corrected so, that's why I do what I do.

These comments and the ones that precede them point to at least two paths to politicization for consumers and survivors. First, they may base their new way of seeing the world on their own experiences which take on greater significance when shared with peers. Alternatively, they may witness others' experiences and through these vicarious means, come to embrace a politicized identity. Either way, their new-found mistrust and doubt require validation. "Few people have the strength to stand up for what they believe in the face of almost unanimous opposition" (Chamberlin, 1978, p. 75). There is an extraordinary pressure on consumers and survivors to see their problems as exclusively of their own making. The express purpose of psychiatric diagnosis is the appropriation of individual experience in preparation for translation into medicalized terminology, thereby fulfilling the twin goals of localizing the problem as within the "diseased" person and capturing it for professional intervention (Evans & Stoddart, 1994). But, as Janeway states, it is a suspicious circumstance when biology appears to be a destiny only for the powerless. By coming together to share stories and create bonds, consumers and psychiatric survivors have discovered what Susan Marshall did -- that their experiences have something *in common*. Obviously, once the discovery is made, one form of protest is to turn their backs on the whole thing and leave, get out, get "well." However, the respondents in this study have chosen to stay, in large measure because they have access to an heretofore unavailable avenue for expressing dissatisfaction -- political activism and non-violent protest (Gil, 1996) in the form of the consumer and psychiatric survivor movement. Indeed, respondents affirm, in colloquial terms, that their experiences have left them "fighting mad." As some feminist survivors have said:

> "Our anger is real. Our anger at our experiences of oppression as women and as psychiatric inmates, of being raped, beaten, locked up, drugged, shocked, is valid and strong. It is not a 'symptom' to be drugged or therapized away. It is, instead, our source of power, a fuel for our outrage and our activism. " (Raymond, Lear, Bostick, Bradford, Chamberlin, Price & Dumont, 1982, p. 8)

In conclusion

De Certeau (1984) states that "the acceptance of a limitation is the foundation of a social contract" (p. 64). Donna puts it more clearly. She says people tend to think that "if you asked for help, you should put up with whatever you get." Asking for help carries with it an implicit agreement between the powerful and the powerless that the right to protest, complain, or perhaps even comment on what's offered is forfeit. However, fundamental changes in social power structures that relate to new, more egalitarian ways of distributing knowledge have created an opening for do-it-yourself alternatives to the psychiatric system (Toffler, 1980; 1990). After a process of re-capturing their own identities, consumers and psychiatric survivors have had the previously denied option of sharing their stories among one another. As a result, they have awakened a collective sense of anger in response to what they view as the trauma of many forms of psychiatric "help." However, as these stories demonstrate, respondents appear unable to identify these sorts of changes as powerful expressions of agency which are capable, at least potentially, of great impact. In addition, Cassin (1993) warns that a movement founded solely on grievances has a limited future because it can only survive by finding more and more complaints to sustain itself. Nevertheless, consumers' and survivors' highly visible and often critical presence at all levels of the Ontario mental health system, recent though it may be, has definitely had an effect. One of the more interesting effects has been their stance towards mental health professionals. Given that for literally centuries, psychiatrists and other professionals have defined who consumers and survivors are, it is indeed interesting to see how consumers and survivors, in their long awaited turn, define who mental health professionals are.

CHAPTER 7

THEM

The evolution of an identity that is independent of the one that has been developed by the dominant forces "creates boundaries between an 'us' and a 'them' (Gamson, 1991, p. 42). From a philosophical perspective, de Beauvoir (1949) states that for there to be an "I," there must also be a "you." In other words, a subject requires an object and, in de Beauvoir's pioneering feminist example, women are the object of men's subjectivity -- they are Other. The primary characteristic of the category Other is that its members have no substance of their own except in relation to the dominant subject. They have only a secondary role to play in the project of life. They are not, however, useless because they are the mirror in which the male subject searches for his own reflection. Subjects and objects, like men and women, have a relationship which in Janeway's (1980) language is called a power contract.

The psychiatric gaze has historically rested upon a group of people who now call themselves consumers and psychiatric survivors and who, in the last few decades, have begun to gaze back. The struggle to reappropriate their own "spoiled identity" (Goffman, 1963) and celebrate it individually and collectively, as Janeway advises, has meant the development of a group history. It includes a set of "mythologies" which defines a site for the launching of an embryonic subjectivity, complete with a clear picture of its own version of Other. The consumer and psychiatric survivor category of Other is composed of psychiatrists and other mental health professionals.

In the following pages, I examine how respondents define "them." I describe the underlying motives respondents attribute to them which are then employed as explanators of their behaviour. Respondents offer their speculations as to why mental health professionals can be seen to have good intentions, mostly, and yet things continue to go wrong. I conclude with a discussion of the "system" which appears to be a metaphor for the power contract between consumers, survivors and mental health professionals and I provide an example of what happens when the system fails.

This chapter represents one of the surprises that is so often a part of research. I was well aware of what "we," as professionals thought of "them," the patients, at least from the perspective of my own experience as a staff person in a psychiatric hospital, but I didn't anticipate the pivotal role that professionals play in consumers' and survivors' internal and external life worlds, although de Beauvoir certainly would have. She states, "Once the subject seeks to assert himself, the Other, who limits and denies him, is none the less a necessity to him: he attains himself only through that reality which he is not" (p. 157). Psychiatric survivor Chrystine Cassin (1993) adds, "*We* create an image of *them*: we look in our mirror and affirm that we are not like *them*. *They* do the same thing with respect to *us*. When we begin to refuse to allow them to re-mold, re-create us into their image of what we ought to be, then the battle lines are drawn" (p. 375). Respondents' views of "them," which form the basis of this chapter, give a clear indication of what consumers and survivors believe to be the reasons for the failure of the psychiatric power contract.

Invisibility

People who reside within the universe of obligation may not be transgressed against without consequences. However, actions against outsiders are often ignored or may even be legally sanctioned (Gamson, 1995). Exclusion from the universe of obligation requires a visibility which is accorded the group but, paradoxically, denied the individual.

In consumers' and survivors' lives, there appear to be four aspects to invisibility. First, there is the type of invisibility that can serve as a protective measure employed to evade the scrutiny of the powerful. This sort of invisibility offers only relative safety and the cost is silence (Gamson, 1995). In the previous chapter, Donna described what happens when an inpatient shed her invisibility in order to complain about her hospital treatment.

Consumers and psychiatric survivors report that complaining, when not in an institution, more typically invokes the second aspect of invisibility -- being discounted. Esso Leete describes it this way: "I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can voice my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even an ex-client is to be discounted" (as quoted in Deegan, 1990). Bonnie Burstow (1992) offers a concrete example of what can happen when patients are discounted. In the early 1970s, a woman patient of James Tyhurst, the psychiatrist who lent his name to the Tyhurst Report discussed in Chapter 4, complained of blatant and cruel sexual abuse involving master-slave scenarios, forced fellatio and whippings. Tyhurst was not charged until approximately fourteen years later when three more former patients came forward with the same or similar stories. Tyhurst's defense was that his patients were delusional and, therefore, could not be believed. He was only convicted because experts agreed that the complainants' diagnoses, borderline personality disorder, did not involve delusions adding that, had they been schizophrenic, Tyhurst may very likely have been set free (Burstow, OPSAnews, #!, 1992). As a second illustration of this type of invisibility, one of the present study's respondents offers her views on the experience of being discounted:

> Well, ultimately there's that "thing." I had someone say it to me explicitly. I was doing some Board development work at an organization and a woman looked me right in the face and said, "You're mentally ill. How do you know what's good for you?" And I think that pretty much sums it up. It just doesn't matter what you say because everything is pathologized. I tell someone to fuck off, I have an anger management problem. A normal person tells someone to fuck off, they're just angry. You know what I mean? Everything we do is pathologized. I do this work (at a drop in centre), and the shrinks tell me, "You do that work to avoid facing your own issues." So, I don't do this work, then it's something else. I'm avoiding responsibility, whatever. Once you get the label, you're pathologized so you just might as well accept that everything that comes out of your mouth is going to be questioned and it's not going to be legitimated, so I accept that as a given. I'm not working on a premise that anybody takes me seriously and I try to go from there.

Consumers and survivors also report that they experience invisibility when they seek help from the mental health system. The following speaker is Sue Goodwin who, at thirty-two, sometimes wonders why she is still alive. She suffers from permanent brain damage due to the after effects of a severe head injury sustained in the following way:

> I threw myself in front of a subway when I was twenty-three because I was still going through all the flashbacks and memories of sexual abuse and

> thinking nobody loved me and there I was, a successful woman with a job and a husband and going places in my career and I jumped in front of a subway at lunch time. Because I still had the thought from childhood that nobody loved me, you know? The system didn't help me because I had been going to see a psychiatrist while I was at work and I was on masses of medication to zip me up in the morning and to calm me down at night so that I could function at work, as a wife and as a social being with friends. And it just didn't work. All that so called intervention didn't help a bit because nobody talked to me and nobody listened.

The final aspect of invisibility is experienced as a result of interactions with "them" in consumers' and survivors' political role. Cassin (1993) calls it the "vanishing principle" (p. 374) and Jennifer Chambers offers an example:

> The first time I was at an event that included mental health professionals and I was there identifying as a survivor was a conference that we had about four years ago. It was amazing to me because I had been studying in the mental health system as a student and I'd worked in the system as a researcher -- and my experience when people knew I was a survivor was so different. I was so ignored! I was in a session looking at, what was it now? I think it was education or something. The session was chaired by a psychiatrist and one of the things I was trying to suggest was that the language should be changed so that when they talk about expertise and education, instead, talk about knowledge and experience which would include first hand knowledge. And although he wrote down everything that everyone else said, when I spoke, he wouldn't write it down. Other people in the room started to notice. I was even saying, "You could write that down.. right there... under that category." And it didn't matter. It was as if I wasn't speaking. It was eerie.

They hate emotion

Respondents reported that the one thing guaranteed to make mental health professionals uncomfortable is a display of emotion. Walter Osoka lives in London. At the time I spoke with him, he was studying at Fanshaw College, hoping to get work in the social services. He says, " I show emotion which people hate, especially service providers. They hate emotion. Why is that?" Jennifer Chambers diagnoses the problem as follows:

> People have to be prepared to go through some pain in order to move forward and something the mental health system teaches people is NEVER to allow that to happen. If you feel pain, immediately suppress it with drugs.

Indeed, in recent decades, critics of psychiatry argue that, by emphasizing biological factors in the etiology of mental illness, the profession has turned increasingly to pharmacological solutions and electro-convulsive therapy to the neglect of wider social and psychological contexts of patients' lives (Breggin, 1991). Childhood trauma, disturbing life events, violence, poverty, loss and grief are seen as affecting the course of illness (Goff et al, 1991) but are relegated to marginal status in psychiatric treatment plans (Waring et al, 1990; Beiser, 1990; Joffe et al, 1989). These concerns may figure more prominently in the paradigms of the other mental health disciplines but this sort of compartmentalization of life experience leaves people like Susan Hardie and Marilyn Nearing feeling "divided up." Susan says:

> Professionals offer a kind of segmented helping. They say, 'I can only give you this much. You now have to go to the social worker for that, or the nurse for the other thing' and each may call themselves 'person-centred,' but I am fragmented and my whole person is not dealt with. They're always saying, 'That's social worky kind of stuff so we can't do that together. I do therapy kind of stuff.' So I'm left running around in circles because I just don't know where the answer is.

Susan's experiences are perhaps indicative of the fragmentation in the professional mind. Indeed, now, as in the past, the professional view on the role of environment versus biology in the etiology of mental illness is "divided up," often expressed as a duel between conflicting sets of research findings. Reminiscent of R. D. Laing, Peter Breggin (1991), a contemporary anti-psychiatry proponent, calls mental illness "psychospiritual overwhelm" and places a strong emphasis on the need for professionals to understand patients' emotional lives. To shore up his argument, he meticulously documents the flaws and misconceptions that he feels pass for bona fide psychiatric research findings. In addition, Illich (1975) argues that the paramount goal of the medical enterprise has been to "detach pain from any subjective or inter-subjective context in order to annihilate it" (p. 93). In doing so, it has also usurped control, separating the individual sufferer from the responsibility inherent in the management of his or her own pain. Illich believes that pain, in all its forms, is a challenge to human beings which calls them to attention and forces interpretation. It poses a question which cries out for an answer. It makes people think, as well as feel. Sometimes it must be endured and at other times, conquered, but it always requires a response even if that response can only be courage.

Donna would concur. She states:

> You have to learn that your pain is part of you. I'm not saying you should cheer about the atrocities that have happened to you but they're part of what makes you the person you are. I think you have to learn to deal with that stuff, to live with it, to accept it and move on. We know there's not a lot of evidence that cognitive therapy does anything. I really believe that all therapy is, is picking scabs to watch them bleed. Clients never get better and therapists are just picking, picking, picking. People always feel crappy in therapy. So, I think you have to learn that it's OK to be where you are, that you don't have a disease, that you're not different from other people, and that you have value.

However, many respondents report that they were unable to "accept it and move on," as Donna advises. "If I'd known how to make myself feel better, I would have done so long ago" says Jane Pritchard, a twenty year veteran of multiple admissions to psychiatric hospitals. Jane is a former librarian who maintained her employment between her inpatient stays and has only recently retired. She speaks of the pain in her life before she entered the "system:"

> The only way I had of coping with my life was to be seriously depressed. I lived with that for many years and finally, one day, I said, "I can't live like this one moment longer. I guess I have to die." I thought I had to kill myself because I didn't know there was any way of helping me to be anything other than depressed. However, that was such an incredibly.. such a serious decision, I thought about it and I said to myself, "Well Jane, once you do it, you don't get to change your mind, Surely, there must be someone out there that you can go to for help. I figured I needed help from the experts. However, that's not what I got. I got abuse. All kinds of abuse.
>
> Susan Hardie describes a similar experience this way:
>
> Most of my energy was going into just surviving and I wasn't able to contribute to my community, to society in the way that I knew I could. So it was a constant struggle and it just got worse and worse. I mean, I was trying, but I didn't think I could do it myself. I thought that I must need to know something else, something outside of me... My whole life just seemed out of control.. So in 1989, I reached out for help, hoping that the professionals would listen and actually work with me but that's not what I got. It didn't matter what I felt. What got lost was my personhood.

Walter concludes that professionals hate emotional pain because that's "the way they've been educated." He goes on to point out how men's pain may not, in fact, be ignored. Instead, it is misinterpreted.

> Have you ever heard this? What's the flip side of depression? Professionals call it anger. If you're depressed... especially if you're a

> guy, what you really are is angry, This is what I was told. I'm not making it up! See, if I have any type of emotion, if I cry it's because I'm angry. If I laugh hysterically, I'm angry. If I hug somebody, which I don't do very well, but if I show any kind of emotion, it's because I'm angry. If I was to give a speech, if I show emotion, if I break down and I cry or whatever because I'm so emotional about a certain thing, it's not because it's something that was very dear to me, it's because I'm angry.

Church (1993) agrees with Walter when he says that mental health professionals are educated in such a way as to suppress their own and others' emotional lives. She believes that professionals feel required to conform to a certain behavioral code which she describes as: "Don't give offense. Don't be unpleasant or adversarial. Don't complain or fight. Be nice. Be reasonable. Be considerate. Be cooperative." (p. 210). Church concludes that professionals trade in their ability to express emotion, especially anger, in return for membership in the inner circle of power -- the universe of obligation. On the other hand, psychiatric survivors, in both their patient and political roles are not constrained in the same way. She quotes one survivor as saying: "Most of the unwritten rules affect the mental health professionals rather than us survivors.. We don't have jobs that are at the mercy of anyone... We have nothing to lose, absolutely nothing to lose and everything to gain" (p. 218). While it must be noted that these comments were made prior to the advent of the Consumer/Survivor Development Initiative which, today, employs many consumers and survivors in jobs they would be loath to lose, they are nevertheless instructive. Having nothing to lose, while typically the most powerless of social positions, can in some circumstances constitute a powerful advantage. Consumers and survivors need not hold their tongues or quell their emotions in fear of losing status. In addition, having at one time or another acquired the label "crazy," they can, if they so chose, exploit with relative impunity the political potential of this stigmatized identity, locating themselves outside the reach of many of the social niceties, courtesies and polite interactional rules that professionals must follow. In fact, the occasional "bad manners" of loud, emotional confrontation give consumers and survivors a powerful edge (Church, 1996).

It's just a job

Albrecht (1992) states that life's problems are expressed in sets of social relationships which, by themselves, have no formally acknowledged meaning. Meaning is attributed only when responsibility, language, symbols and values are assigned. If a problem is given a psychiatric meaning, then solutions are to be provided by the mental health system. In other words, it is a system that depends on the appropriation of life problems for its existence and while it is the individual that feels the distress, it is the system that defines the need. And these needs are great and ever increasing. "The health care industry ... is one of the largest clusters of economic activity in all modern states" (Evans & Stoddart, 1994, p. 27). By extension, it is also one of the largest employers of professional helpers.

Chamberlin (1978) believes that there is a fundamental difference between help which is offered altruistically, from one human being to another, and help that has been professionalized. When helpers are financially rewarded for caring, it is natural and, perhaps, even necessary to suspect a conflict of motives. The end result of the formal, paid mental health system is that it creates and perpetuates a chasm between the well, normal helper and the sick, abnormal patient. Chamberlin states, "detachment and impartiality, which mental health professionals believe are the proper therapeutic attitudes, become, in practice, either cold formality or the shallow pretense of friendliness" (p. 149). Asking for help, she concludes, will never be shorn of its inherent humiliation until our culture recognizes that all people need help and support at some time in their lives and, when they do, it is normal to ask for it.

Patrick Brown was born in Jamaica but has lived in Canada since he was a teenager. When he first entered the system, he felt that it would take a month or two to get back on his feet. "But to my surprise, it took me fifteen years to get to that place. I don't think that anybody could have snapped their fingers and got me well. I think it was a process." At thirty-eight, Patrick now works at a job opportunity project for consumers and survivors. He says he has met a lot of good people in the system but the person that helped him the most wasn't a psychiatrist or a professional. It was a friend.

> I think the people who are the most effective are those who are compassionate. We need more empathy and you can't pay somebody to be empathetic – you can't pay somebody to care. It has to come from the heart. I mean, if you are making $50 an hour working as a therapist and they decide to give you $200 an hour, you might do something differently but I don't think it would make you a more empathetic person. Money changes people, but I don't think money can change things like that.

Hugh Tapping argues that the advocacy efforts of mental health professionals are also suspect because they have competing interests – what they say they want on behalf of "us patients" is closely tied to the things that promote the status of their own profession. Hugh is a survivor of the "good old, bad old days," spending his seventeenth birthday in a psychiatric institution receiving numerous rounds of ECT. He is also a veteran of the mental patient liberation movement of the early seventies. At forty-six, he says that the best way to describe him is to say that "words and wit are not necessarily the same as wisdom." He offers his view on how professionals promote their own self interest.

> For example, when professionals began to talk about the "mentally ill" rather than the insane, this was just an earlier version of what is, today, called politically correct language. The public doesn't care about these kinds of terms -- they're mostly irrelevant to them. The idea of being "mentally ill" didn't come from us. It was another one of these top-down things done by professionals who are in a position of privilege and power. It's biggest result was that it reduced a lot of the stigma of working with us crazy people. It used to be that, you work in the loony bin, people look at you funny just like they look at us patients and now, well, gosh, you must be a nice, helpful, professional. And of course, this was also correlated with a rather significant across-the-board increase in income levels for those non-medical doctors we call psychiatrists.
>
> Donna says:
>
> There is no one fighting for the rights of the mentally ill unless you count the caregivers and then that's a completely different story. What we're talking about is a growth industry in a time of diminishing career paths. So, they say people are best stabilized in a community-based crisis program and it's clear that their next job will be in a community- based crisis program, well... I'm not saying this to be cynical. I don't think professionals are in this with malicious intent, but you have to, at all times, question their motives. They're coming from a skewed vantage point.
>
> Jennifer Chambers gives an example of this "skewed vantage point:"
>
> The power of the written word is not overlooked by the powers-that-be. For example, our article in the Toronto Star about rights violations at the hospital -- the next day the associate administrator had been by our office about five times and wanted to meet about it and he said he was very upset about this article about rights violations and we said, "Why don't

> you get upset about the rights violations instead of being upset about seeing it in print?"

These study respondents seem in agreement with the oft repeated consumer and psychiatric survivor charge that the mental health system profits from their misery. Patrick argues that human compassion is not for sale. Others add that, when push comes to shove and jobs or reputations are at stake, the professionals' economic well-being will come first. But, as Jane Pritchard says. "if they would just do their jobs, do what they are paid for -- listen to us, treat us like human beings with brains and emotions, and provide real help" then the integrity of the power contract would be preserved.

They are abusive

True to their historical tradition, consumers and psychiatric survivors also seek to expose abuse in the mental health system. Contemporary activists make the distinction between two levels of abuse. First, there is what they would call sanctioned abuse, psychiatric treatment itself and second, there is abuse that would be called criminal by anyone's standards.

In a 1990 broadcast on the CBC, Irit Shimrat, aided by many of her peers, talked about the types of abuse -- as they define it -- that passes for psychiatric "help."

> "Last year, I was picked up by the cops. I'm a small person. I weigh 118 pounds. They tied me in four-point restraint to a stretcher in Mount Sinai Hospital here in Toronto. I kept getting out of the restraints and eventually I was put in a leather harness and that's when I was injected with Haldol. I was paralyzed from the waist down. I couldn't talk. My jaw was completely locked." (p. 2)

> "The medication was so heavy, none of the patients knew what was going on. And when my children came to visit me at the Royal Ottawa, they wept because Mummy was so out of it." (p. 5)
>
> "I calculated I had at least 50 or 60 insulin shocks. It succeeded in making me scared as hell and I shut up -- it worked by inducing fear." (p. 4)
>
> "They ripped my clothes off and stuck me in the bum with needles very painfully and roughly because I was struggling to get away from them..." (p. 11)
>
> "I was rendered instantly unconscious. My body, a few seconds later, entered into convulsive seizures. A lethal electrocution consists of one ampere for one second through your brain. What we're talking about is more than half of a lethal electrocution, each and every time. This is called therapy." (p. 19)

Many respondents had their own stories of abuse to tell, some of which are reported in the preceding chapter. Hugh Tapping adds:

> It's all very well to acknowledge that many people come from abusive families but who's going to acknowledge that abuse goes on in institutions and by professionals. Are we going to acknowledge that when you're in a disproportionate power relationship that disproportionate things happen in these relationships? Whether you're a kid or an adult, when you're driven crazy by an abusive situation in your family, you are likely to be forced into an abusive situation in an institution. And if you get your act a bit more together and you go looking for an "alternative" therapist -- although I've got a lot of respect for what a lot of people do -- I don't see any more quality assurance mechanisms in place in a community agency than I see in the run-of-the-mill big, bad institution.

The second type of abuse is that which is defined by the Roeher Institute Report (1995). It highlights the extreme vulnerability of people who are dependent on their caregivers. In the context of this study, one respondent described one such experience as follows:

> I flipped out once and my landlady called the police. I was self-injuring. I have a history of self-inflicted violence. And that was the one time the police took me to a hospital but there were no beds so they took me to this other "safe" place and one of the other people staying there raped me. So I thought, well, this is fucking crazy, right? Like, this system is fucked. On the streets, I know how to take care of myself. Locked in this place, I can't take care of myself.

Some respondents, however, felt that professionals don't intend to be unkind and abusive. They just don't get it. Walter Osoka says:

> The whole idea of professionalism is fine except that they are stuck at doing a certain thing a certain way and sometimes they don't look at the broader picture. I think professionals, and by that, I mean psychiatrists, don't look at the broad view of it. It's kind of like, "Take a Prozac and call me in two weeks." But I'm hungry. I have no place to stay. I have no friends. I have no communication with other people. "Well, that's OK. This will make you fine anyway."

Patrick Brown also believes that they really don't mean it:

> A lot of injustices are done in the name of psychiatry but I don't think those injustices are purposely done. I don't think the psychiatrists or the professionals or the social workers or whatever set out to be unjust. It's something that happened by chance or happened because they didn't take the time to listen. They didn't take the time to analyze the situation.

Donna concurs:

> What I realized was that the caregivers are not hurting us intentionally. They buy into this. They believe that they have the answers.. that they have the education, that they've read exactly the right number of books they need to tell somebody what's wrong with them and to fix them. They *believe* that. What they don't realize is that people are dying because of it.

Janeway (1980) is not as lenient in her views of the motivations of the powerful. She states that what they want to do is remake the minds of their subjects but "the mind can only be remade in one way, by recapitulating the process of socialization through which individuals learned the world and came to maturity" (p. 207). Certainly, Hugh Tapping refers to what he sees as the inter-connectivity of abuse in families, institutions, and community mental health services. People fleeing abusive families, he says, find themselves in abusive psychiatric hospitals and, upon discharge, in abusive boarding homes and, potentially, in abusive community-based programs. Other respondents also alluded to the frustration they feel when they ask for help and find that the factors that precipitated their distress in the first place are recapitulated in the "help" they are offered. Miller (1983), in speaking of professional education, says that it's no wonder that people who, themselves, have spent years in repressive institutions of higher learning victimize their patients and clients. "Students.. are spending four years at the universities learning to regard human beings as machines in order to gain a better understanding of how they function.. (instead of) unmasking the devastating consequences of the way power is secretly exercised under the guise of child-rearing" (p. 278). She concludes that because children are punished for awareness and understanding, as adults, they give up the quest, preferring the false safety of ignorance while, in shame, repeating the same acts of violation that they, themselves, were once victims of.

Viewed through the eyes of consumers and survivors, mental health professionals, in general, are not an attractive group of people. They espouse a narrow and inaccurate "caregiving" paradigm which discounts the views of the people they are supposed to be caring for. They are cut off from their own emotional lives. They are either unthinkingly or maliciously abusive. They look out for number one and, if threatened, quickly drop what appears to be only a thin veneer of high minded altruism in favour of the cold hard cash of a pay check. They develop institutions, programs, theories and treatments that recreate and extend the very problems they are supposed to ameliorate. In short, "they" seem to provide an excellent background against which consumers and survivors can create the foreground of their new identities -- "we" must aspire to be everything "they" are not.

But they're more like us than they think

As respondents looked into the mirror provided by their observations of mental health professionals, they noted that what they often saw was themselves. Marilyn Nearing says:

> We had a week long workshop with consumers and mental health professionals in attendance and I heard them saying the very same things as us. "I'm not in control. There's no money... no support." There were front-line staff who clearly didn't know what their agency budgets were. They weren't taking personal responsibility just like consumers don't take responsibility over their own medications and their own therapy. I saw that commonalty between the two. The same sounds of hopelessness. The same sounds of dependency. It rather frightened me because if the front-line staff aren't empowered, how can they can pass the power along to their clients?

Jennifer Chambers offers her observations:

> A woman counsellor that I knew gave a talk at Queen Street on sexual abuse and ritual abuse saying that what is often seen to be psychosis can be flash backs and to the staff she said, "Abuse is widespread. Some of you have been abused. If you haven't dealt with that, you're not going to be able to help anyone else." Well, most of the staff walked out. The *insistence* that they are different from the people they serve is so strong.

During her many inpatient stays in a psychiatric hospital, Jane Pritchard says that she often felt alone and suicidal and what she longed for was someone who would "talk to me, listen to me. Help me understand me." She reports that, occasionally late at night when things were quieter, the nurses might sit with her but the topic of conversation was *their* troubled lives, not hers. These professionals concluded that the kind of help they were offering in a mental institution would never be the kind of help they would seek for their own difficulties.

> I recall one nurse telling me about her sad life and she said, 'I'm seriously considering committing suicide myself but, let me tell you, Jane, I'd never put myself in the position you're in.'

Chamberlin (1978) states that the enormous distance between patients and staff in mental institutions makes "meaningful human contact difficult or impossible" (p. 201). However, these types of honest conversations do occur from time to time, revealing that staff are people who have problems too. But, as Jane's experience indicates, they also recognize that placing themselves in the very helping hands that they represent is humiliating and shameful and, as a result, likely to be no help at all. Walter Osoka offers a variation on this theme. He feels that if mental health professionals, themselves, understood through their own life experiences what it was like to need help and support, they might be more compassionate. He says, "It's my hope that people who work in the mental health system will say, 'I've had problems too,' because if they would do that, maybe getting help wouldn't be such a scary thing." Marilyn Nearing adds:

> When you look at the really caring and committed professionals, you'll probably find out that they've had some sort of family or personal experience that has sensitized them. I think that when professionals start

> to admit they belong to the same group as us, we will have a better chance. Unfortunately, a lot of professionals are terrified to do that. Just terrified -- and for good reason. They are kind of on the outside. They walk a tight rope. The unique ones that I admire and who have affected me so positively and affected so many others positively, well, they really aren't well rewarded by their profession. In fact, I've seen professionals lose their job for being too honest about how close their own personal experiences are to ours.

While respondents can see that professionals, like they, are people who have problems and, in addition, often feel powerless in the face of authority, they did not recognize what, I would argue, is another similarity. Even as respondents lamented professionals' tendencies to stereotype them as a single faceless and falsely homogenous category, when given the opportunity, consumers and survivors, themselves, stereotype professionals in much the same fashion. In addition, "good" mental health professionals who were seen as having provided real help didn't appear to be part of any category at all and for the purposes of this research, slipped quietly off stage while the "us" versus "them" battle raged. Indeed, throughout the study, helpful mental health professionals did not figure into respondents' conversations in any substantial way, unless brought forward as an example of the rare exception that served to prove the rule. This lack of acknowledgment blinds consumers and survivors to a potential source of allies for their cause and, in addition, pre-empts a possibly fruitful discussion about what, exactly, delineates "good" and helpful professionals from their supposedly "bad" and unhelpful colleagues. It also ignores the reality that "good" professionals, just like their "bad" colleagues, can have their own entrepreneurial agendas for change which may or may not agree with consumer and survivor goals. Cassin (1993) concludes that defining the category of Other as a uniform and often unattractive "they" is part and parcel of the politics of activism but the mutual tendency to stereotype can militate against the identification of positive opportunities for cooperation and collaboration between the powerful and the powerless.

The system

De Certeau (1984) argues that it has been the project of sociology to examine those aspects of human experience which have not been "tamed and symbolized in language" (p. 61). People's everyday lives are full of activities and relationships which, if they are pressed for an explanation, seem best described as "the way things are." In other words, there are many instances when "we do not know what it is that we know" (p. 63). In the preceding chapter, consumers and survivors described a process by which they came to "see" and "know" themselves in a new way. In de Certeau's terms, they had discovered the language to describe that which they knew but could not say.

In this vein, there is a word that continues to crop up and with such frequency that it seems to demand explanation, yet none is forthcoming. That word is the "system." Consumers and survivors describe themselves as still in the system or completely out of the system. They argue for change in the system or, alternatively, suggest that the system should be blown up and replaced with something new. They describe what the system did to them and fear for their peers who are left behind in the system. They fight the system, they complain about the system, they advocate from within the system, they reject the system and they blame the system. Consumers and survivors are not alone. Mental health professionals also use the term and with at least equivalent frequency.

We work in the system, we support the system, we advocate on behalf of the system, we rebel against the system, we reform the system, we talk about getting out of the system and, like consumers and survivors, we blame the system.

What is the system? In Janeway's terms, it as a reified metaphor for the power contract. It is the relationship between "us" and "them" and, as such, it is an extremely difficult thing to see and to know because *we* are *it* (Simmel in Levin, 1974). In order to know and to see the system, de Certeau suggests what he calls an old recipe, whereby a specific example is "cut out" from the surrounding cloth of the larger more opaque concept and "made to talk" (p. 62 & 63). The example I have chosen to begin to know and see the system is Cedar Glen.

Hugh Tapping was the only respondent who mentioned Cedar Glen. He attended the inquest. Usually, when a subject is raised only once in a study, it is assigned small importance because qualitative data analysis techniques depend heavily on uncovering themes and commonalties among the majority of respondents' experiences. Occasionally, however, just one instance is revealing and, as a consequence, demands a place of its own in the research story. Cedar Glen is a case in point.

In 1984, Jean Thibault and his wife Mary Jane purchased a boarding home called Cedar Glen for $250,000 from the Dyke family who, after fifteen years in the business, had decided that they wanted a change. It was by all accounts an attractive, well-run home for twenty-seven ex-mental patients, most discharged from two provincial psychiatric hospitals, Queen Street Mental Health Centre in Toronto and the Penetanguishene Mental Health Centre in Orillia. The house was located in a small village called Uptergrove, not far from Orillia and about two hundred kilometers north of Toronto. Not long after the purchase, the public health department and the fire marshal noticed that the home had begun to deteriorate, failing its health and safety inspections three years running because of violations such as locked fire doors and well water contaminated with fecal coliform bacteria (OPSAnews #2, 1990).

The condition of the residents was not, however, a matter for concern until May of 1985 when a former Queen Street patient, Ron Eaton "escaped," as he was later to describe it. Somehow, he made his way back to Toronto and Queen Street Mental Health Centre where he told the Patient Advocate Office that he had been beaten by the owner, Mr. Thibault. A subsequent medical examination showed that he had sustained two broken bones. The institution's Patient Advocates contacted the Ontario Provincial Police in Orillia repeatedly, twenty-three times to be exact, but they professed themselves to be powerless to take action due to what they felt was the lack of credibility of the witness (Inquest finding, 1990). In December of the same year, a second resident, 56 year old Jean Smith, was rushed to hospital covered in bruises and suffering from a severe head injury that resulted in an 11 month long coma. At this point, the police reconsidered their earlier position and charged Thibault with two counts of assault, allowing bail only on the condition that he stay away from Cedar Glen (Toronto Star, Jan, 1988). Queen Street staff also visited the home to ask the remaining residents if they wanted to be moved but they said no, they were fine. Staff concluded that, given that Cedar Glen was a privately owned home, they were powerless to remove the residents unless they clearly stated that they wanted to leave. Later, Pam Dyke, the former owner, was quoted as saying, "(Thibault) supplies you with your food, with your every necessity of life. And he threatens you that if you don't say you want to stay..., What are you going to say?" (W5 transcript, 1988, p. 6)

In the summer of 1987, Doreen and Randy McCunn, as new graduates of the social service program at a nearby community college, sought employment at Cedar Glen and were deeply disturbed by what they witnessed. Thibault, in violation of his bail order, had continued to visit the home, often in a drunken rage. The McCunns witnessed Thibault, his wife Mary Jane and their teenage daughter regularly beat and verbally humiliate residents. They were locked out of doors in winter clad in very little clothing. The bathrooms were barred at night and residents were punched and kicked when they urinated on the floor. The few residents who tried feebly to escape were returned and beaten. A broomstick was used to batter the testicles of one of the men. Women were forced to sit on chairs while Thibault hit them repeatedly in the face. The heat was turned so low in winter that the residents constantly shivered while the Thibaults wore coats indoors. Food was rationed and the residents often went hungry. Heavy doses of psychiatric medication, prescribed by a local doctor, were administered twice daily, often by the Thibault's teenage daughter (Toronto Star, Jan, 1988). Welfare and old age pension cheques were seized in their entirety, leaving the residents with nothing. The Thibaults' annual income was reported at $156,000 and, in just three years, they amassed enough profit from the operation of Cedar Glen to purchase a separate home on a one hundred and ten acre farm, complete with barns, cattle, farm machinery, several cars, and a swimming pool (W5 transcript, 1988).

When the McCunns tried to arrange an interview with the Ministry of Health so that they could reveal what they knew, they got nowhere (OPSAnews, #2,1990). They persisted for three months and eventually went to the press in frustration. W5, a well-known public affairs television program agreed to look into the story. At the same time, the Ministry of Health and Queen Street staff decided to take action. They notified the families of the residents that Thibault had been convicted of the assault charges against him but some had already read about it in the newspaper. Then, on New Year's Eve in 1987, Queen Street staff accompanied by a Ministry of Health bureaucrat, removed the residents from the home whether they said they wanted to go or not. W5 cameras recorded the scene as part of a television show which they called the "House of Horrors" that went to air in January, 1988.

Unfortunately, these actions came too late for Joseph Kendall, a former Queen Street patient who died, ostensibly from a blood clot on the brain, a month and a half before the W5 cameras arrived. When the police ordered his body exhumed, it was discovered that the death certificate had been inaccurate. When admitted to hospital, Kendall had been suffering from pneumonia, malnutrition, dehydration and a reaction to over-medication but what actually killed him was a massive pulmonary embolism due to post-operative complications when surgeons had attempted to repair a hip fracture sustained in an altercation in Cedar Glen (Inquest findings, 1990). Soon afterward, Thibault, his wife and teenage daughter were charged with various counts of assault and in September, 1989, Thibault received a three and a half year prison sentence while his wife was sentenced to four months. The daughter, as a juvenile, was placed on probation (Packet & Times, July, 1990).

Joseph Kendall's death was the subject of the longest inquest in Ontario's history, running for four months in late 1990 (Packet & Times, Oct, 1992). Held in Orillia, there was relatively little publicity although the local paper picked up the story and followed it through to its conclusion. Several family members sued Queen Street Mental Health Centre, an individual staff member, the Ministry of Health, the Ministry of Community and Social Services and a second individual social worker who worked for adult protection services in the Orillia area (Packet & Times, July, 1990). The charge was that Queen Street staff and other government officials had known about the abuse but had failed to take action to protect the residents. The suit was eventually settled out of court for an undisclosed amount of money (Swadron, Personal communication, 1994).

However, the conclusion of the coroner's jury was that no one person or set of persons could be held accountable for the Cedar Glen tragedy. While it expressed itself to be "shocked and appalled" that such a thing could occur in Canada, its verdict was that it was the "system" that had failed Joseph Kendall and his fellow residents. The jury's recommendations covered every professional group, agency and body that had been involved as the sad story unfolded. Among the lengthy list, was a call for a number of new laws, some of which were to be designed to force professionals to report abuse. Another set were to create a system whereby individual advocates must be assigned to "vulnerable adults" to see that their rights are not violated and a suggested third set of laws were to be focused on the licensing of boarding homes so they could be regulated by government staff. In short, the jury accepted the contention that the many professionals who knew about the conditions at Cedar Glen yet who had failed to take action were, indeed, powerless. Instead of individual culpability, it was the system that was judged to be at fault (Packet & Times, November, 1989). Consequently, the solution was cast in terms of more laws and more staff to enforce them. In fact, the jury's recommendations were remarkably swiftly and thoroughly acted upon. A commission to look into unregulated housing was immediately appointed and a report, "A Community of Interest" was released in June, 1992 (Packet & Times, 1991). It formed the basis of Bill 120 which was designed to extend the rights of tenants under the Landlord and Tenant Act so that they also applied to vulnerable adults in unregulated housing. In December of the same year, the Advocacy Act[1] was passed calling for the establishment of a 23 million dollar Commission employing 130 professional advocates (Packet & Times, Oct, 1992). At the same time, the Substitute Decisions Act and the Consent to Treatment Act were also passed (Packet & Times, Dec 8th & 10th, 1992) and although complex, both were designed to "expand the rights of adults who are mentally incapable" (Guide, 1994, p. 6).

When Hugh Tapping speaks privately of Cedar Glen, he assigns blame and names names. His memory of the inquest is filled with files suddenly gone missing, inexplicably poor memories and a general look of terror on the faces of the professionals who testified. However, in an article published in OPSAnews (#2, 1990), he is more reticent.

> It would be easy to blame the Ministry of Health for what went on at Cedar Glen.... It would be easy, and it would be wrong. There are Cedar Glens in every province and state on this continent. The level of violence was the only unique thing about this particular one. (OPSAnews #2, 1990, p. 9)

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[1] One of the first tasks of the newly-elected Conservative government was the repeal of the Advocacy Act which was accomplished in March of 1996. In addition, the Substitute Decisions Act and the Consent to Treatment Act were combined into the Health Care Consent Act which, in essence, wiped out the expanded rights and obligations called for by these two separate pieces of legislation (Guiffreda, Personal communication, December, 1996).

Jennifer Chambers, speaking of instances like Cedar Glen and other examples of what she terms "cowardice in action" points out that, in fact, everyone has something they fear losing. She says,

> Everybody's afraid. With service providers, it's obvious. They're afraid of losing their jobs. With people who still rely on mental health services, they are afraid that what little they have will be taken from them. People say, "If there's abuse going on, why don't we hear about it?" In the hospital, it's obvious why patients are afraid of complaining. It's like domestic abuse... well, in some ways, it's worse. For someone to complain about someone they're living with takes an extraordinary amount of courage, but when people can be involuntarily returned to the institution they may have complained against, there's reason to be terrified.

Schwartz (1994) states that when bad things happen in the "system," the typical government response is to create more rules and regulations because it is the only thing that it knows how to do. Certainly, the uniform rationale among those that had knowledge of the plight of the residents of Cedar Glen was that they were powerless to intervene because there were no laws that allowed residents to be removed from a privately owned home if they were unable to say specifically that they wanted to go. However, as Mrs. Dyke, the former owner countered, why didn't government and hospital staff have the empathy and wisdom to understand that the residents' couldn't possibly openly defy the violent Thibaults? Why didn't the moral imperative supersede the legal one? Alice Miller (1984) answers. She states that it is the well-raised child, the obedient and compliant child who is in particular danger of abandoning autonomous thought and action in favour of the sanctioned path of rules and regulations. In adulthood, these children may attain Wartenberg's (1990) social shell of outward power, composed of university degrees, important jobs, and respected titles. However, when tested, it is the child's remembered sense of powerlessness which surfaces, evoking feelings of danger and vulnerability, overwhelming independent judgment. To do as one is told is the price of membership within the universe of obligation and when there is no rule to follow, the safest course of action is to do nothing.

There is a curious silence among consumers and survivors regarding Cedar Glen. Many simply don't know about it but this, in itself, is odd given that a detailed report, sparing none of the ugliness, was published in a widely circulated survivor-generated newsletter (OPSAnews #2, 1990). Cedar Glen offers the clearest, publicly acknowledged and most thoroughly negative portrait of "them" available, yet it has not been embraced as a plank in the activists' platform. Certainly, the legislative flurry that followed the incident entailed the enactment of laws which consumers and survivors had heretofore only dreamed possible. However, laws are blunt instruments and Hugh Tapping concludes his article on Cedar Glen with a note of discomfort which had seemingly begun to sound in his mind. He says, "Legislation can make it easier for people to do their jobs. But how can a law make people care?" (OPSAnews #2, 1990, p. 9).

There is the possibility that what happened at Cedar Glen offers more "knowing" and "seeing" than is palatable for consumers and survivors. If "they" are afraid and "we" are afraid, who's in charge? Some respondents believe that the system represents a power contract that can never work. Donna says, "It's my hope that people will figure out there there's nothing here, that professionals talking to you and reading books and taking counselling courses can't change what's in your mind." Chamberlin (1978), a long time proponent of self help and survivor-run alternatives to the formal system, agrees. But there are others who, like Jane Pritchard, say, "if they would just do their jobs..."

In conclusion

The Scottish poet Robbie Burns wished that God could grant us the gift to see ourselves as others see us. He was probably alone in this. Most of us have no desire to hear the unvarnished opinions of "us" offered by "them." Consumers and survivors typically enter the mental health system through the doors of psychiatric hospitals where it is routine and, in fact *de rigueur*, for professionals to offer written and verbal assessments of them. My own experience taught me that we tend to see patients as sick, manipulative, non-compliant, unmotivated, ungrateful, hopeless and helpless. When the tables are turned, and consumers and survivors are in a position to offer their assessments of us, they judge us to be willfully deaf and blind, emotionally constricted, misguided at best, abusive at worst, and when threatened, sycophantic and cowardly. In addition, they say that we disguise our own vulnerabilities and despise the very help we are supposed to be giving. The system, as the place where "we" and "they" interact, seems to make us all, as Jennifer Chambers says, afraid; afraid of losing our jobs, afraid of losing what little we have, afraid of saying what we think and afraid to tell. However, as the next chapter reveals, consumers and survivors are as hard on each other as they are on mental health professionals.

CHAPTER 8

US

As consumers and survivors continue to find one another and share their common experiences and grievances, they are challenged with the task of formalizing their association. Gamson (1991) states that any group or movement that "hopes to sustain commitment over a period of time must make the construction of a collective identity one of its central tasks" (p. 28) -- consumers and survivors must become an acknowledged "us" which is demonstrably different from "them." Implicit in a collective identity is a sense of solidarity -- group members must hang together so they don't hang separately, as Janeway (1980) puts it. Chamberlin (1978; 1990) is adamant that self help is the most natural rallying point for consumers and survivors and, indeed, these sorts of groups are an excellent breeding ground for social activism (Gamson, 1991). In Canada, however, self help has been slow to develop. Church (1993) states that it is difficult to know just how many self help groups exist but in 1988, she conducted a national survey which found about a dozen that were active.

The Canadian document, A Framework for Support (Trainor & Church, 1984), identified self help as only one component in the construction of an appropriate mental health system and, by virtue of its central theme -- a redefinition of the mental patient as citizen rather than service recipient, -- tended to concentrate its emphasis on a call for a central role for newly-named "consumers" in the planning, development and delivery of all mental health services. This publication was quietly received until it was put to the test during the consultation process that led to the Graham Report (1988), precursor to the formal government policy document called Putting People First. At that time, consumers and survivors became intensely involved with professionals under the rubric of *participation*. Consequently, in Ontario, any discussion of the development of a group identity for consumers and survivors must be played out against the backdrop of the hovering presence of "them" -- mental health professionals, bureaucrats and other government figures.

In this chapter, I attempt to answer the second question of the present study: How have consumers and survivors translated their personal experiences into a collective identity focused on political action? Second, I examine the question of whether or not respondents feel that they are part of a wider social trend, one that could be called a social movement having the qualities, perhaps in embryonic form, of the peace, environmental or women's movements. I also look at the Consumer/Survivor Development Initiative (CSDI), a Ministry of Health funded program which received 3.1 million dollars in the spring of 1991. This program, in concert with the Advocacy Act, the report entitled "A Community of Interest" which examined unregulated housing, the Substitute Decisions Act and the Consent to Treatment Act constituted what, at the time, could only be considered a windfall of government-sponsored pro-consumer activities which were, arguably, the legacy of the Cedar Glen tragedy. Finally, I discuss a high profile CSDI funded project, the Ontario Psychiatric Survivors Alliance (OPSA) which received almost half a million dollars in committed, ongoing government funds in the summer of 1991 and lost it two years later amidst dissension and acrimony within its own membership.

Getting involved

Susan Marshall, who told her story in Chapter 6, said that when she realized that she wasn't alone in her experience of the psychiatric system, she began to get angry. However, the journey from ex-mental patient to consumer or survivor is, for many respondents an assisted one, in that very often, mental health professionals were involved in some fashion. A respondent who wished to remain anonymous explains:

> Mine is kind of a funny story. I never thought of myself as a consumer/survivor or had any kind of identity like that. But, at the Employment Office, I saw something put up by a local Toronto agency. They were looking for a project manager who was familiar with issues around personnel and human resources, and someone who had knowledge of the mental health system. I had no concept of consumer/survivor. I thought I was just a fuck-up... just couldn't get it together. A failure, right? And so anyway, just for a joke, I fired off this resume and I said that I would discuss my knowledge of the mental health system with them in person. Well, they called me for an interview and they said, "What about your knowledge of the mental health system?" And I kind of laughed to myself because I didn't think they would want *my* kind of experience but I answered anyway. And one of the guys interviewing me said, "You're a consumer/survivor." Fortunately, the meaning of the term was kind of obvious to me, so I said, "Yeah, yeah. That's what I am." So a mental health agency made me a consumer/survivor. Now, there's a turn of events!

While this respondent identifies her recruitment by a mental health agency as a "consumer/survivor" as unique, she is no way alone. Susan Hardie, also, was directed toward involvement in the system by a mental health professional.

> I came out of my personal experience with the psychiatric system feeling that I had failed as a person. With the help of a psychiatrist -- he encouraged me to look into the system and try to understand the workings of it -- I began to understand that I could get involved and bring about some change versus, before that, I kind of felt that it was really hopeless. I was in very much of a victim mentality.

In fact, mental health professionals were typically instrumental, directly or indirectly, in respondents getting involved in the system. Given the emphasis on participation that had, by the time of my research, enshrined itself formally in Ministry of Health evaluation procedures for mental health programs and agencies, it is not really surprising that professionals played such a prominent role in consumer and survivor recruitment. Yet, Patrick Brown perceived his experience this way:

> It was really an accident. I was taking treatment at a hospital and a staff member there said, "You know, Patrick, I'm starting a little group called the Input Committee." So this person asked me to sit on the committee and I started participating and, you know, she felt that I was a very good contributor. At the time, I had just recovered from a breakdown. This gave me an opportunity to express some of my feelings about the system and the treatment I had received. And then she told me that there was someone from another organization looking for a survivor to sit on a another committee. So I went to talk to these people and they were very kind, supportive, very understanding and were looking for honest input from survivors and that's how I became involved and it kind of just mushroomed from there. I was asked to sit on the Board and then, you know, I started getting exposure and people just started asking me to do things so, it wasn't really something that I had planned. It was just something that happened.

Other respondents pointed to a government sponsored conference called Our Turn, held in Montreal in November, 1989, as particularly transforming. Adele Rosenbloom helped organize the event. She was a thirty-nine year old mother of two boys and a self-described Jewish, feminist activist who started having problems at a point in her life when she was identifying as a lesbian, a lifestyle that her mother disapproved of. Because she worked in a group home run by a feminist collective, she was able to rely on her co-workers for support and assistance during her most difficult periods, but her mother felt that treatment from the formal mental health system was in order. She suggested that Adele accompany her to a hospital with the promise that a psychiatrist whom Adele had found to be helpful would meet them there. However, once they arrived, it was revealed that it had all been a trick to get her admitted. Frightened and angry, Adele tried to run, but she was picked up by the police, certified by the duty doctor, restrained and given Haldol by injection. She was held for eleven days on a psychiatric ward. Adele says:

> It was after that experience that I got involved in organizing the Our Turn conference. Survivors from all across Canada came together with funding from the government and we had a wonderful time. We met in Montreal for about five days and really, that whole event was so empowering and liberating. I felt truly supported and understood. I came away feeling strong and I lost a lot of the shame that I felt as a result of being locked up. For me, it helped build self esteem again.

Dave Stewart, staff to the Patient Council in a provincial psychiatric hospital in the eastern part of the province also attended the conference. Dave describes himself as a problem kid -- the "black sheep" of the family. "I had no self worth, no self esteem. My family had already disowned me, emotionally anyway, and I was experiencing great bouts of depression. Suicide was an obvious way out." Hospitalization, to Dave, meant being put away for the rest of his life. But, as he says, "I was a bad patient" so he was let out. He describes his experience of the Our Turn conference this way:

> What struck me initially was seeing and hearing from others about the things I believed in or what I had experienced from my history in the system. I wasn't alone and that was really the first time I had felt that. And then it just so happened that when we returned from the conference, the politics in Ontario were such that my involvement increased in the early 90s. My area was one of the pilot projects that sprung from the Graham Report and, of course, everybody was looking for consumers, as they called us then. And I happened to be one who had gone public and a few people knew of me and gave my name to others.

For other respondents, their formal involvement as a participant came when they were hired by one of the many newly funded Consumer/Survivor Development Initiative (CSDI) projects. Paul Reeve says that he saw an ad in the paper and he was amazed. "Here was a job where you *had* to be an ex-mental patient to qualify and all you had to do was declare it." Louise St. Jacques, writing in the OPSAnews (#7, 1992) echos Paul's surprise. "I never dreamed that being labelled crazy would land me a job." Donna adds that, in fact, she had never thought of herself as a consumer until a job came up that listed direct experience of the mental health system as a requirement. Susan Marshall, as well, credits a job as the impetus for her involvement. And, as Paul indicates, all people had to do to compete for the three hundred[1] mostly part-time jobs that were originally created through CSDI was to declare that they were ex-mental patients.

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[1] In 1995, these numbers had shrunk to 161 employed in 36 CSDI projects province-wide (Dewar, 1995).

Certainly, these sorts of opportunities afforded those who chose to "go public" the possibility of a new and more valued social role; as "partners" or, as it is often termed, "stakeholders" instead of marginalized ex-mental patients. Participation also meant that consumers and survivors began to have a substantial presence in the mental health system due to the kind of power that sheer numbers can provide (Arronowitz, 1992). Indeed, CSDI funding created consumer and survivor controlled projects all over the province and each could be said to equal what Berger (1977) calls a mediation structure -- a mid-sized organization or association that serves as a bridge between the individual and the large institutions of society. In fact, the CSDI programs became visible recruitment pools to which mental health professionals and government bureaucrats could turn when seeking stakeholders for the many activities related to mental health reform. The new demand that consumers and survivors sit side-by-side with professionals and bureaucrats as they planned changes in mental health services signaled a substantial shift in the traditional power contract between these groups. Participation also afforded large numbers of ex-mental patients an opportunity for influence which historically had only been achieved through the precarious authority of the lone-wolf advocate. However, some respondents reported that "going public" was a heavy price to pay for their new found status and the jobs attached to it. Susan Hardie offers her thoughts:

> The doctor I was seeing was really supportive and helped me weigh the pros and cons of going public. Now, I kind of regret... like, what did I do by letting people know I was a consumer? It's blocked all these avenues for me but then, I had the opportunity to weigh the pros and cons. A lot of times, because of the amount of funding for consumer

> projects, especially in Ontario, people just jumped in with both feet because they could get a paying job by revealing they were a consumer or a psychiatric survivor. Sometimes they haven't even weighed the implications.

Susan Marshall feels that she has been able to handle the stigma but she worries about her daughter.

> She's been affected. We're a small town here. It's not like being in Toronto. There are a few of her playmates who are no longer allowed to come to our house.

Marnie Shepherd, a survivor herself and a staff member of the CSDI program, agrees with Susan when she says that life in a small town can be difficult for self-identified consumers and survivors. She says,

> I work with a group that's in Smiths Falls and when they looked for office space, it couldn't be on the main street. It's a small community and everybody knows when you go in that door where you are going. So they're off the main street and they're in a small building that has some other services in it that aren't related to mental health so people can come in. In rural Ontario, consumer/survivors struggle with the stigma.

The issue of stigma aside, some respondents seemed embarrassed to admit that their sensitization to the consumer and survivor movement came about because of a job, indicating that, from their point of view, it wasn't quite a pure enough motivation. In fact, eleven out of the study's thirteen employed respondents were working for some sort of government-funded consumer and survivor project -- most of which were sponsored through the Consumer/Survivor Development Initiative and an additional three had worked previously for such programs. In fact, CSDI funded a total of 42 advocacy or economic development projects across the province in the first few months of operation. Given Church's 1988 survey where only a dozen ex-mental patient groups could be found in Canada as a whole, this level of activity represents a clear demonstration of the impact of government funding on consumer and survivor activism.

Gamson (1995), states that it is not uncommon for groups who have been excluded from society's universe of obligation to have their fate reversed. For literally centuries, no one has much cared what mental patients thought or believed. However, in the early part of this decade, the Ontario government seemed to have begun to care deeply and, as a measure of good intention, assigned a small dollar figure (in the overall scheme of things) to demonstrate its good will. The governmental view of consumers and survivors is rife with those sorts of paradoxes that merit close attention. In one set of laws, it endorses a *parens patriae* philosophy, providing the legal avenue for suspending the civil rights of people who are judged to be mentally ill. On the other hand, it actively recruits these same mentally ill people to participate in the production of public policy. Although it is a large question, the notion of why now? requires some consideration. One clue may be that consumers and psychiatric survivors are typically critical of professionally-dominated mental health services, particularly psychiatrists and institutions -- the more costly components of the health care system. Continually rising costs require countervailing measures based on a logic that tax payers can assimilate as reasonable justification for either capping expenditures or cutting back. Customer dissatisfaction is a saleable rationale for downsizing the institutionally-based portion of the mental health system and modifying the rest. Also, consumers and survivors tend to advocate most strongly for really cheap things such as self help and economic development projects and, as a result, these sorts of alternatives are enjoying a new emphasis in formal government policies such as Putting People First. In addition, they are supportive of less-expensive community-based, non-institutional services because it is among these types of programs where essentials such as housing are offered. In fact, it has been my experience that it has been here, in this service sector, where mental health professionals have been the most welcoming of consumer and survivor involvement. There are a number of reasons why this may be so. First, community mental health programs are typically small and, as a consequence, organizationally more manoeuvrable than large hospitals when it comes to instituting change. Second, they offer the kinds of practical, daily-living kinds of services (housing, drop ins and case management) where workers do not maintain the extremes of social distance from their clients that are characteristic of the formal professional-patient relationship. In addition, there is the perception among community-based professionals that they share a compatible value base with consumers and survivors and thus, participation is considered to be, relatively speaking, less challenging of the status quo. And finally, given that consumer and survivor involvement is a government-endorsed direction, community programs may see their uncomplaining compliance as providing them with a productive conduit through which they can advance their own entrepreneurial aspirations.

Pressures such as fiscal restraint, along with a general reduction in admiration for experts and an increased emphasis on prosumerism (Toffler, 1980), combined with the utility of a consumer dissatisfaction logic, provide a synchronicity of motives that, speculatively, may offer at least a portion of the answer to the question of why, now, consumers and survivors are enjoying, at least, a symbolic reversal in their typically marginalized status. A further point which merits mention is the recent availability of a socially-valued political activist role for ex-patients. This new role has provided the means whereby former patients can remain involved in the mental health system. Historically, their choices were two-fold; stay as a sick and shunned service recipient or get well and get out, all the while taking steps to disguise a shameful past. However, Dianna Capponi (1992), in a keynote address at a CSDI conference, argued that consumers' and survivors' new role and sudden popularity is not as enjoyable as it may seem. It is her view that it has sapped the energy from a nascent social movement, preventing it from developing the strength that a slow step-by-step evolution would provide while, at the same time, redirecting much-needed humanpower and very scarce emotional resources towards eternal wrangling with government bureaucrats over funding issues and other complaints related to the mechanics of participation.

Is this a social movement?

Consumer and survivors often use the term "movement" when referring to themselves in the collective sense. Social movements have become part of the fabric of contemporary social life with the term loosely applied to a multitude of protest and reform activities (Mayer, 1991). I thought it important to ask the study's respondents if they felt that what was happening among consumers and survivors could be called a social movement in the same way that the peace, women's or environmental movements are. Not surprising, given Dianna Capponi's remarks, their answer was, "maybe." Sue Goodwin, as a survivor of both the psychiatric system and a serious suicide attempt states:

> Well, *something* definitely is going on. Survivors are <u>still</u> at the point where they don't believe in themselves enough to band together in a big movement and, you know, march down the middle of Church Street as the gays and lesbians do on their Pride Day. Psychiatric survivors have been punched down everywhere; by their families, by their church, by the system and once that happens to you, as it happened to me, you don't speak out on your own behalf. You speak out in little groups or to other survivors who can identify with you and, once in awhile you get to speak to the government. Well, you can speak to them but they don't listen.

Marilyn Nearing adds,

> I think that consumers and survivors feel that they have been vulnerable and have suffered a kind of stigma which is every bit as strong as racial prejudice. I think all prejudice is tantamount to being labelled and over-generalized and I think we're rebelling in almost the same way. We're saying. "Look at me as an individual, value me as an individual." -- which is about what every social movement has been founded on.

Jennifer Chambers says,

> I think it's similar in the sense that it starts off with people coming together to share their experiences and to consciousness-raise about common issues. That's the necessary first step and it has to happen over and over again in the different places that survivors are. So there's the desire to be on our own which is in common with the women's movement. And lately there have been some events like survivor festivals. We aren't so much focused on a particular goal.. Like all movements, retaining focus in the face of the overwhelming number of things that need doing, is a challenge.

Susan Marshall saw a clear connection with other movements.

> Definitely this is a movement. I think the similarities are that we began with no rights, absolutely none, and we have had to agitate for them. It's the same with the women's, peace and with the environmental movements. They've taken something that's just had no recognition, period, and made it a popular cause. Well, we're not yet a popular cause but we're moving along those lines.

Walter Osoka is less optimistic. He says,

> Well, if it's a protest movement, it's one that's very quiet. You don't hear about it over the TV or the radio or any other type of media. I'm not blaming anybody. I just think it could be more vocal. In fact, listen to this. Have you *ever* seen a headline that reports a murder and then goes on to say and, oh, by the way, the prime suspect is being treated for diabetes. That's *never* said, is it? But if the person was being treated for mental illness, it's *always* mentioned. This is our public image.

In an additional comment, Sue Goodwin presents herself as being on Walter's wave length.

> Nobody knows what a consumer or a survivor is. If I go around saying I'm a consumer, they think I work for Consumers Distributing. And if I say I'm a survivor, people say, "Survivor of what?" The truth is that nobody in the whole wide world understands what a consumer or a survivor is.

John (who preferred to be identified only by a pseudonym) adds:

> I'm not sure if you could say it's a social movement because, although there are some isolated pockets of people doing things, I think there must be, what? 95% of the people who are not connected with activism or don't have the resources to do anything like that. A lot of them are just too busy surviving. They're busy from day to day, trying to get food and lodging. They have different interests than the people who have a fairly good quality of life and who have time and health and resources to set up protests. A lot of people feel very powerless.

Hugh Tapping feels that there's no cohesion.

> At present, most of these committees have "individuals" on them, they have "people" on them.. they are atoms, right? If they belong to some sort of a group, then they're not supported in working with that group. Most are not even aware of a movement let alone feel part of it.

Patrick Brown looks at it from another angle. He feels, like Alvin Toffler does, that society, itself, has changed. It is now ready for a new kind of activism.

> I don't think it is a movement that consumer/survivors themselves have started. I think it came out of society becoming more aware of the fact that not every consumer/survivor fits the image of the typical stereotype like somebody walking down the street barefoot, eating out of a garbage can. I think society has realized that survivors or consumer/survivors, whatever term you want to use, are people that probably had a breakdown once in their life and recovered and can make a contribution. Vincent van Gogh had a mental illness. Winston Churchill, too, and the list goes on. It's a natural social process. It's not something that was pushed ahead by any one group of people.

Jane Pritchard, like Hugh, is more pessimistic. She says. "By virtue of the fact that we have a common bond, a common experience, we have a movement but we haven't gotten our shit together, to be perfectly honest and blunt about it." Jennifer Reid, who told her story in Chapter 6, agrees.

> This movement is thousands strong but we're not united and until we are, we're not going anywhere. If we were united, we could stop Yonge Street. We could just sit down and say, "No! We don't want this crap anymore." But we won't do it. We're afraid of losing our jobs, or afraid that the government will stop our welfare checks. We're afraid of losing our housing and of going back into hospital. And we're afraid that if we're known as a political agitator, we'll get held in hospital longer.

These comments seem to indicate that, while there are definitely shared experiences and grievances among respondents, they feel that they have not developed the kind of solidarity that other movements enjoy. However, there is some evidence that they have, at least, *begun* to form a movement. For example, the Ontario government and mental health professionals in general have recognized them individually and collectively, formally and informally, even if motives are tangled. Second, their newly acquired access to previously forbidden territory such as Boards of Directors, task forces and government committees has increased their potential for influence exponentially. In fact, their simple presence in places and situations where professionals and bureaucrats used to confer in private has forced a shift in the nature of the traditional power contract. A prime source of evidence for this shift lies in the language changes that characterize mental health reform rhetoric and writing, an example of which is the use of the term "survivor" in government policies and documents, a politicized acknowledgement which so angered doctors and psychiatrists that they have protested vigorously, but without result (OPDPS, 1994). However, study respondents seemed unable to recognize these effects. One reason may be that the changes they envision are so much greater than these largely symbolic victories that it's hard to celebrate so little when so much remains to be accomplished. Certainly, Jennifer Chambers states that it's very difficult "retaining focus in the face of the overwhelming number of things that need doing." Additionally, consumers and survivors have a heightened sense of urgency that drives their desire for change. Having "been there," they contend that their peers are dying while planning exercises go on and on (Church, 1996). This sense of immediacy makes honouring small incremental gains difficult. Further, having become accustomed to viewing the world from the bottom up position of marginalization rather than the top down position of system planning, consumers and survivors have little faith in words, viewing concrete action as the only solid evidence that real change is underway. In addition, given their heavily stigmatized public identities outside the narrow world of mental heath reform, combined with the extreme paucity of their monetary, emotional and human resources, consumers and survivors are coming from a starting position which could be said to be far behind that of members of other movements. While involvement in government committees and agency Boards may offer some reward, the reality is that many consumers' and survivors' lives remain characterized by poverty, unstable housing, unemployment and the possibility that they may, once again, find themselves in the very institutions they have so vociferously attacked. In this latter situation, their newly acquired power and status doesn't go merely unappreciated, it becomes a potential threat to their safety.

Consumer? Survivor? Consumer/survivor? Or just a person.

So far in this work, I have been careful to use both consumer and psychiatric survivor when speaking of respondents. I have also occasionally thrown in the hybrid version, consumer/survivor. Church (1992) states that this latter term was invented for a paper entitled "Do the right* thing right" (1990), published with her co-author, a prominent ex-mental patient activist and former Member of Provincial Parliament, David Reville. While terms such as consumer or psychiatric survivor may appear to be simply a utilitarian way to communicate the changed status of ex-mental patients, in reality, each designation has a loyal following in a hotly contested political identity debate.

The naming of oneself or one's group is a political act because "domination and colonization attempt to destroy our capacity to know the self, to know who we are" (hooks, 1989, p. 31). Mental patients have typically had their identities defined by mental health professionals -- being labelled as some consumers and survivors call it -- having acquired the term from Thomas Scheff's (1966) work on labelling theory. Labels are psychiatric diagnoses; schizophrenia, manic-depression, borderline personality disorder and so on. However, psychiatric diagnoses are prone to becoming an enveloping identity (Estroff, 1989). In fact, it is rarely said that a person has been diagnosed with schizophrenia. Instead, he or she is called a schizophrenic. In addition to these formal labels, mental health professionals often call mental patients other things such as manipulative, unmotivated, ungrateful and non-compliant. And finally, the general public has a variety of names; crazies, nutbars, looney toons, weirdos and psychos.

In Chapter 6, Marg Oswin states that she believes that mental patients experience a unique form of oppression when the site of colonization is the mind, one that reduces them to nothingness -- a cipher, as she calls it. The special bond that is created out of this experience has inspired ex-mental patients to re-claim and name their own identity so that they can, at one and the same time, capture the uniqueness of their oppression, while also rejecting vehemently other people's labels. The construction of a political identity is a complex matter in our present-day social world where there are a multiplicity of choices available related to people's membership in a variety of different collectivities (Moghadam, 1994). Certainly, gender, race or ethnicity are irreducible sources of identity (Aronowitz, 1992) but beyond these visible characteristics, people may choose the level of emphasis they wish to accord their potential group loyalties. The purpose, however, of creating an identity is to produce an "us" with a shared history and belief system (Papanek, 1994; Smith, 1994). *Consumer*, as discussed in Chapter 4, is a designation that grew out of literature that focuses on the rights of mental patients as citizens (for example, the Framework for Support, Trainor & Church, 1984). It is a rather mild-mannered term that attempts to empower patients and clients by equating them with customers -- a term which, in the sphere of the market place, denotes people who are respected because they demand satisfaction or else they take their business elsewhere.

On the other hand, psychiatric survivor, with its much more in-your-face connotation, was coined by ex-mental patients, themselves. It is intended to convey strength in the face of adversity, a sense of optimism and independence, and, above all, power. Without exception, this study's respondents identified themselves as survivors. Consumer was considered a term that the professionals had thought up. "It was imposed by the government," is Sue Goodwin's view. Walter Osoka adds. "Consumer means that you actually buy it." Indeed, this was the most common view of who a consumer is -- someone who consorts willingly with the enemy without benefit of the political analyses that survivors have developed. Jennifer Chambers adds that "consumers tend to be people who believe in mental illness while survivors look more at the social causes of people's distress." Consumer also means dependence. Patrick Brown states:

> They depend on the system for the rest of their lives. From the day they get sick to the day they die, they're consuming services. That's what a true consumer is.

Another respondent felt that the standard market place meaning of consumer simply doesn't apply in this case.

> It suggests that there's this huge psychiatric shopping mall where you can go and pick your services. So, it implies a choice when actually the choice is very limited and, in some cases, there is no choice at all.
>
> She adds:
>
> And the second reason that I don't like the term is that it suggests that all we do is consume, that we're always taking, where I think that I also contribute something to my community.

Jennifer Reid concludes the discussion succinctly. She says, "I didn't consume the system. The system consumed me."

On the other hand, the term, psychiatric survivor, had an emotional commitment which was evident in the many sub-meanings that respondents accorded its definition. For example, eight respondents specifically identified themselves as survivors of child sexual abuse which, from their perspective, gave psychiatric survivor an intended double meaning -- survivor of child abuse and survivor of the mental health system. Marilyn Nearing says,

> Most of us are survivors because we have survived tremendous amounts of abuse in our lives. The prevalence of abuse among members of this movement is extremely high. And I don't any longer take it as a given that all of us do survive -- a lot of us haven't. I take great pride in that word and I wear it like a medal.

Indeed, Marilyn is not wrong in her belief that child abuse is a common experience among current and former psychiatric patients. In a review of eight studies involving 587 women psychiatric patients, findings ranged from 65% to 97% reporting severe child abuse. When sexual abuse alone was examined, the figures ranged from 37% to 65%, indicating an extensive problem (Beck & van der Kolk, 1986; Bryer et al, 1987; Steiner Crane, 1988; Chu & Dill, 1990; Firsten, 1991; Muenzenmaier et al, 1993; Goodman, Dutton & Harris, 1995; Zlotnick et al, 1995). Further, in a study of 125 men psychiatric patients (Swett, Surrey & Cohen, 1990), it was reported that 48% had experienced child abuse with 7% reporting sexual abuse although there is always speculation that men under-report abuse, especially sexual abuse, due to fears that they might be thought gay or have been caused to be gay (if the abuser was a man) or of ridicule (if the abuser was a woman) (Lew, 1988).

The second aspect of the survivor identity is surviving the system. Jennifer Reid says,

> I'm proud of being a survivor. I use the word survivor because the psychiatric system rapes people and if you get raped, what are you? You're a survivor so that's why I say I'm a survivor.

An additional meaning attached to the term survivor was the idea of surviving what *might* have happened -- those things that respondents felt that they were lucky to have escaped. Donna explains,

> I had a very bad go a few years ago now and I was pretty dysfunctional but I was married to a man who could afford to support me so when I quit my job because I really couldn't get up in the morning, it was OK. All the things were in place to just let me dwell in my sorrow, if I can put it that way. And I understood from my earlier experiences, if I could just hang on, it would pass. Now, it took a long time, but it did pass and my point is that if I can avoid the system because of my social economic situation, then obviously it's being used for the lepers of today -- the throw-aways. The whole institution is built around poverty. It's not built around need. The bottom-line is that the only thing that saved me happened to be my socio-economic position and that, to me, is terrifying. It was the only difference between what could have been done to me and what wasn't done.

Another respondent who prefers to be identified only as M. echos Donna's point.

> Seeing people who are wearing the only jeans and the only shirt they've got and smoking the one cigarette they're going to have for the day and nursing the one cup of coffee they're going to get... I walk away from that and see it in my head for a long time and it takes its toll because there is so little I can do to make it better. There but for the grace of God, go I. Had my birth been different, had my upbringing been different, had my education been different, had my illness been different, I mightn't be where I am today.
>
> Patrick Brown adds,
>
> When I'm down at the hospital where I used to get treatment, I see people that I knew ten years ago and they're in the same state. They haven't regressed or progressed. That's a wasted life. I'm not better than those people, I want to make that totally clear. It's just that some of the opportunities I've gotten, those people haven't had.

Patrick goes on to say, that from his perspective, he also survived what he calls, the experiment. "Most of us are guinea pigs, let's face it. Right now, there are a lot of drugs in psychiatry and they don't know how they work." Patrick is referring to the kind of specialized information, formerly available exclusively to doctors, that is now reasonably easy for anyone to access. For example, the Compendium of Canadian Pharmaceuticals, a highly technical reference written with doctors in mind, can be found in most libraries and it says very much what Patrick says, it has not yet been discovered how psychiatric medications work in the brain.

Another respondent, in offering her personal definition of psychiatric survivor, tells how she explained it to her family. She says,

> My parents didn't know about my mental health history, right? I got involved in the system after I ran away from home. So, when I go home now, they're always remarking on my job at the centre saying, "You're

> so great to work with 'those' people." And I couldn't stand it any longer so I said, "Look, I'm one of those people." Well, my mother just kind of shut down but my father said, "Who told you that?" So I went through the whole explanation. I said, "I've got a clinical file, like, a *very* thick file that covers many provinces." So he says, "Ahh, in this country" – he's not from Canada – "in this country, as soon as you stand up and say something, they tell you you're crazy. Everybody thinks I'm crazy too. The guys at work won't even eat lunch with me" And then I tried to explain the term consumer/survivor and he said, "You shouldn't call yourselves that. You should call yourselves, "people who know what's really going on." So that's his take on the whole thing.

Finally, Walter Osoka offers a definition that just about covers the waterfront. He says, "Being a survivor means surviving mental health services, surviving the help we were supposed to get, surviving the stigma, the side effects of the medications, the loneliness, hunger, homelessness, abuse, the illness, itself, and surviving losing your rights as a citizen."

The hybrid version, consumer/survivor, invented by Reville and Church (1990), figured prominently in respondents' conversations but it appeared to have been adopted as a convenience term as well as a form of bridging language for occasions when both groups, psychiatric survivors and professionals, work together. It is the term used in <u>Putting People First</u> and it can be found in a variety of other government documents. However, from the perspective of many respondents, the official sanction of the term consumer/survivor appears to have sapped the shock value from "psychiatric survivor" while, at the same time, politicized-by-association the tamer version, "consumer." Church (1992), herself, says that it seems to have stilled, rather than encouraged debate. Whatever the case, Sue Goodwin says that she's not fooled by any of it.

> The government invented the whole thing. It's supposed to be kinder than calling us ex-psychiatric patients. It's also for people in the movement who object to being called consumers because no one knows what the fuck that is and it's for people who don't want to be called survivors because then people will know that you're a scary mental patient. So they put a slash in between the two things so we wouldn't have an identity crisis.

Indeed, some members of the survivor group feel that their identity has been stolen once again and, in a variety of Internet exchanges, have begun calling themselves crazies or lunatics in an effort to retain a radical edge.

Certainly, the adoption of a political activist identity, whether consumer or survivor, offers respondents a less stigmatized status than ex-mental patient and, as a consequence, access to power and influence previously denied them. However, as Sue Goodwin points out, its utility is virtually non-existant outside the small world of mental health and mental health services. Jennifer Chambers, in introducing her story in Chapter 6, was careful to point out that she is not *only* a psychiatric survivor. Jane Pritchard also talks about how narrow the world can become if all possible identities are divided between consumer and survivor. She says,

> I don't want to just survive. I want to thrive. But even that's silly. If I asked you, Barbara, who you were, you wouldn't say you were a "survivor" or a "thriver" or anything like that. And if I meet friends or family or anyone who's not connected with the mental health system, then I certainly don't describe myself as any of those things. I'm just a person.

Among this set of respondents, the term "consumer" was rejected outright as their choice for an identity. As Marg Oswin says, "there's an interpretation that consumers are soft survivors, tentative survivors, future survivors." There are also much stronger opinions. Hurst (1990) says, "Consumers exist but survivors succeed.... A consumer gives in to advertising, to pressure, and to the wishes of (service) providers. A survivor has fought, endured and triumphed, like a survivor of Auschwitz." (p. 7).

The intense and sometimes acrimonious struggle over these two identities suggests the possibility of the presence of two minds within the individual activists. Certainly, none of the study's respondents were prepared to deny that, at some point or another, they had experienced serious problems and, in desperation, they had eventually reached out for help, "consuming" mental health services, as it were. John says that the thing with mental illness is that you just never know if it might happen again.

> I took medication for at least a year before things improved and even then, I couldn't be sure if it was a spontaneous remission or if the therapy and the medications had done it. There's always environmental and biochemical factors. You can't tell. Here I am ten years later and there are still things I haven't figured out – still things I don't know how to cope with.

Susan Hardie confirms John's sense of uncertainty. "It's the oscillation between hope and despair that we all go through, but a lot of us are closer to the despairing side and we are seeking hope." M. describes it more fully:

> We are the children of Sisyphus. Sisyphus is a mythological character doomed to an eternity of rolling a heavy stone to the top of a hill and every time it gets to the top, it rolls back down again and he has to roll it back up again – for all eternity. Up and down, up and down. And for many survivors, that's their life. They have their good times and then they'll reach the depths of depression, not able to come out of their room for days or, on the other spin off, find themselves wildly hallucinating and out of control.

Even Hugh Tapping, an avowed and long term survivor, repeatedly described himself as "clinically depressed" during his research interview. When I asked him why he was using psychiatric terminology when he clearly rejects that view, he said,

> Well, because when you say depressed nowadays, it doesn't mean much anymore. Calling myself clinically depressed seems clearer than saying I'm fucked up beyond all recognition. It's a short form. I don't think I'm clinically depressed in so far as I'm suffering from a biochemical disorder with some kind of genetic component involving my you-name-it neurotransmitter. I'm hurt and I'm pissed off. Depression and anger, the same thing. Rage at the universe turned inwards. Just because you have all the insight in the world doesn't mean it's necessarily going to help.

In fact, many respondents, in passing, revealed that they still took medication now and again or that they saw a therapist or a psychiatrist so, in terms of everyday reality, the lines between the terms consumer and survivor are much more blurred than in their political iteration. It also points to the likelihood of a competition between the identities of political activist versus that of service recipient. On one hand, respondents believe that the service recipient role requires them to put up with whatever help they get without complaint while, at the same time, they struggle with developing and maintaining a political identity based on an ongoing and vociferous critique of that self-same help -- a difficult balancing act indeed. In addition, it appears that embracing the more strongly politicized psychiatric survivor identity does not insulate people against the fear that they may, one day, need help again. Were this to be the case, where can survivors go? Given their hard-line stance against professionally-run mental health services and psychiatric medication, combined with the belief that they may experience retaliation should they find themselves once again in an institution, their options are slim.

The struggle to name the self is a search for the truth, and "to speak a true word is to transform the world" (Friere, 1970, p. 75). Among this group of respondents, consumer is a name that represents those among them who have, so far, "bought into it" -- naive thinkers, in Friere's terms. Psychiatric survivors, on the other hand, are judged to be the people who "know what's really going on." Each identity, however, is an attempt to make the world "look at me as an individual, value me as an individual," as Marilyn Nearing says. The hybrid term, consumer/survivor, seems to have been a successful attempt to create a common language that facilitates participation in the mental health system, as it was envisioned through the Framework for Support model. However, some survivors fear that the willing adoption of such a term by professionals means that the power behind psychiatric survivor has been watered down to the point where it has lost its punch. A second, unacknowledged possibility is that the regular use of the term is, in fact, a sign that activists are having a visible and powerful effect.

When some of "us" joined "them"

While language is an important site of struggle, so too, is money. When the Consumer/Survivor Development Initiative began operation, it hired five consumer/survivors as staff, and they suddenly joined the ranks of the enemy, so to speak, becoming, essentially, Ministry of Health bureaucrats. However, a bona fide mental health professional was selected to head the program. In fact, the person chosen had had extensive involvement in the Cedar Glen incident but this was not the critical issue that troubled most respondents. Susan Marshall says, "God forbid they would get an actual consumer/survivor to run it and make the *real* decisions. The only way they could sell this idea was to have a "normal" person in there." Dave Stewart agrees. "They couldn't have got the political acceptance even with one of our most prominent leaders at the head." Hugh Tapping is a bit tougher. "The professionals own it. They operate it. If they feel you're out of line, you're gone in two weeks."

The five CSDI consumer/survivors were immediately christened the Dream Team by many of their Toronto peers. The nick name was not intended as a compliment. Instead, it was a reference to a movie of the same name where child-like mental patients, on an outing from a psychiatric institution, are left on their own in a rough part of the city and end up having cute adventures. In other words, the CSDI "Team" was considered to consist of naive dupes hired to parrot the agenda of the professional in charge. Marnie Shepherd, one of the survivor staff members, reflects on this perception of her and her colleagues.

> I spent a lot of time in the first year feeling angry because we'd hear people saying CSDI *was* the professional in charge. I felt a lot of consumer/survivors were doing a disservice to us, assuming that we were just complacent. I was in the job a month when one survivor met with our boss over a beer and told him that he knew why I and my colleagues had been hired. He said it was because the Ministry knew that we were just compliant consumers. If somebody said that about me today, I'd still be hurt but I'd have a tougher skin. At the time, I was devastated. But, I've had more than one person tell me that we were selling out.

The Consumer/Survivor Development Initiative was governed by a number of specially developed Ministry of Health rules that consumer and survivor groups had to follow if they wanted funds. First, the projects could not mimic professional services. Help and support for program members could be provided only through an egalitarian self help approach -- Chamberlin's notion of the most natural rallying point for consumers and survivors. Second, projects had to aim towards independence as soon as possible. This meant that, although they might have been given a home with a professional agency during the start up phase for administrative purposes, they were to work towards incorporation and the recruitment of their own Boards of Directors as a priority so that they could be free of professional influence as soon as possible. Third, they were to hire consumers and survivors exclusively, with one or two narrow exceptions. Board and committee members, elected democratically from a general membership, also had to be consumers and survivors, although this last rule has recently been relaxed. While the CSDI rules appeared to have quite thoroughly taken consumer and survivor views and philosophies into account, respondents were critical, remarking that these sorts of stipulations were an authoritarian statement on how the government expected power to be handled in the CSDI projects. Marilyn Nearing says, "They're afraid that we'll get into the same sort of power dynamics that have been perpetuated by the medical model. It's a knee jerk reaction to the mental health system -- a grand experiment." Jennifer Chambers agrees but adds the point that the CSDI projects simply could not be seen as in competition with professional services. She says, "I had a paid position with one of the projects as a peer counsellor and CSDI cut it. We were never able to get a clear answer as to why but all the rumours agreed that it was considered threatening to professionals who did that kind of work." Dave Stewart adds, "I have a feeling that the formal system wouldn't have been supportive of CSDI if the mandate had been anything other than what it was."

Whatever the reasons behind the CSDI philosophy, many groups, some hastily constructed, others with an acknowledged history, succeeded in meeting the qualifications for funding and received what was, relatively speaking, a surprising amount of money. The salaries CSDI was offering were, in fact, attractive by anyone's standards. Many newly employed project staff went from the poverty of social assistance (approximately $7000 to $9000 dollars per year) to quadruple that amount for full-time work. Marnie says,

> I think if I had to do it all over again, I would have advocated for less money the first year because there was just too much and it came so suddenly... to go from having no money to a budget of $100,000 and 2 1/2 staff. Literally, a cheque went out with the only instruction being, at the end of the year, account for how the money was spent and that was it.

Susan Hardie says it was all too fast.

> I believe the intent was good but they were not really working with us at our pace. They're very much quicker. I just see us needing to come together to decide who are we? What are we all about? The additional stressors of the dollars coming in.. we've just been spread way too thin. The bureaucratic and organizational skills are lacking and the few leaders we have had to spend their time trying to do the administrative work so we couldn't do the leadership development like we should have.

Hugh Tapping is a lot more critical.

> You start off with a naive bunch of people. They don't know how to be members of an organization because they have never been in one before. They're not stupid. They just don't know about these things. And then things don't work out right?... shit, we've been broke all these years and finally we got some money and we thought things were going to be wonderful and they weren't.

He goes on to say that many of the projects were incapable of adopting the complex corporate[2] structures that CSDI demanded as the most appropriate route to administrative independence.

> CSDI projects are not *actually* doing it. They might have somebody who is the official treasurer but this person has never balanced their cheque book in their life time. The recording secretary may be functionally illiterate. It's a simulation. CSDI decided these organizations should be independent and the only way to demonstrate that to the Ministry bureaucracy was to tell them that they are all incorporated. It's a lie. Rather than let people struggle along and figure out things on their own, which would risk a lot of personality stuff and a lot of dominance stuff but at least our organizations would have arisen from the perceived needs and the complex interactions of those people who are part of them. Instead, they made them pretend to do this incorporation thing. The point is to put on the pressure so that there's a high turn-over rate within the membership so they can never really get organized.

Hugh is even tougher on the economic development projects funded through CSDI.

> They don't have a snow ball's chance in Hell. All they know about the business world is what they learned in a sheltered workshop in a

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[2] While it is not uncommon for newly formed groups to develop under the wing of an existing organization, these initially friendly relationships are prone to deterioration once serious money is involved. In addition, it is the policy of the Ministry of Health that ongoing funding must be received by a legally incorporated not-for profit organization. Thus, newly funded groups often seek the quick formation of their own corporate structures as an immediate priority so they can be free to manage their own affairs, away from the potentially noxious interference of their original sponsor.

> "rehabilitation" environment. The vast majority of people talk about wanting to have a real job... in the real world, with a real boss and real work to do. If you get paid, you've done your job. If you don't do your job, you get fired... that sort of thing. It's not there for your "mental health." It's not there for your "peer self help." You do a job and get a roof over your head and that's that.

Donna, also, has some sharp criticism. She says,

> I've dealt with three CSDI projects and the premise is wrong. They have what they call peer support counselling and the point is that the members of these organizations have never had peer support. That's part of the reason they ended up in the institution in the first place. How can you provide peer support if you've never had it? I sound like I'm bashing them exclusively but I find the same atrocities go on there as in professional agencies in terms of power. It's just the same, except consumers are being the bullies instead of the health care professionals.

Susan Marshall is a little gentler in her assessment.

> It's kind of like affirmative action in that you're identifying consumer/survivors and hiring them. Even though I can see the necessity for it sometimes, it's got it's own problems. It quite often means that the only reason you get hired is because you're a consumer/survivor and all the other things are totally over-looked like whether you have the qualifications or not. I don't agree with that. I think that something that the organizations are starting to learn as they hire people is that if you don't get someone who can do the work, the organization is going to fail.

Other respondents added a few kind words.

> Ultimately, I think CSDI is a good thing. It's amazing to me that the projects thrive and do as well as they do and the people in the projects are fantastic. They work so hard and they're really dedicated.

John concludes,

> It's a really good alternative to sitting with a therapist once a week and in a lot of cases, it's better.

Marnie Shepherd says,

> I see people with jobs who never thought they'd be employed. One of the people that works here -- when she was in high school, she was told she'd never amount to anything. So having somebody hand her the opportunity to learn how to do financial management has been a real boost to her confidence. I think there's still a long way to go but in lots of communities you see more recognition of there being a consumer/survivor movement -- groups and individuals being called upon more and more to be part of the decision-making although I think there's still a lot of tokenism and people doing what they think they're supposed to do rather than what they really believe in. But, I think on the whole there have been pluses.

One of the final aspects of the CSDI projects that respondents wished to comment upon was its provincial scope. Through CSDI, consumers and survivors from all over the province have begun to connect with one another. In doing so, they have formed opinions about the different challenges that rural versus urban survivors face. Respondents have already commented upon the perception that there is more stigma in small towns. But there are other perceived differences. One Toronto respondent says,

> I couldn't imagine being in Fort Francis. I really admire people that work in that kind of isolation and don't get discouraged and still adhere to whatever ideals and hopes that they have for the organization. It's just incredible that they can do it.

Susan Marshall, who *does* live in Fort Francis says,

> Consumer/survivors in large centres, where the government is -- and that's Toronto and Ottawa -- they're close enough to be right in the know and they're very political. They tend to be, from what I hear, more radical, anti-psychiatry and anti-drug and that's the biggest difference. In order to survive here, we have to work together. Maybe we're politically naive and maybe we get pulled into going along with a lot more stuff.... Toronto consumers always say, "Well, that's part of a big plot to .... whatever" in answer to some of the stuff we do here. My bottom line has always been, well, if it helps just a little, I'm willing to do it.

Marilyn Nearing adds that maybe being far away from the big city is not such a bad thing.

> We often say that if a consumer can't get better in Toronto, where can they do it? They've got five times the services but really, when I look at it carefully, I see that they have more medical model services than anyone. Why should I think that's going to help them? I think the very thing that we're jealous of is impeding them. I have also seen that my counter-parts in Toronto are far more fuelled for fight than we are. I will fight but at the same time I know I won't go looking for it.... but then, I don't have it on my plate everyday either.

Susan Marshall agrees with Marilyn. She says fewer services may not be such a bad thing.

> We don't have services here at all and I think that's been a real bonus in a lot of ways because a lot of people are helped without being psychiatrized, without being institutionalized. Communities get together more and just help. It really, really takes a lot of time and effort to do it that way but it seems to work out better in the end.

Obviously, despite what appears to have been good intentions, CSDI is not without its detractors. Respondents point to a lack of skills on the part of the groups that received the money requiring them to struggle with the complexities associated with running a non-profit organization to the neglect of the self help and advocacy goals which were their founding *raison d'etre*. Also, many of the burgeoning movement's leaders were diverted from their more ideological based functions in order to cope with mundane administrative demands. In some cases, the sheer amount of money received was difficult to handle both organizationally and individually. Visible CSDI organizations became re-defined as places of recruitment for agencies and psychiatric hospitals who, by Ministry decree, had to have consumers and survivors on their Boards and committees. These sorts of demands meant that some project staff and members were "spread way too thin," as Susan Hardie says. Perhaps the most telling result of the CSDI program was that potential solutions to the consumer and survivor community's many problems became defined in terms of money. "More, more, the need is so great" became the familiar and eternal cry, mimicking the common refrain in most mental health professional circles. As one respondent confirms, "CSDI is such a difficult undertaking partly because the amount of funding the groups have isn't nearly what they require to fill the needs of the community."

While respondents' views on CSDI projects are mixed, it must nevertheless be acknowledged that the programs have been designed for and by consumers and survivors, themselves -- completely in concert with the long sought after acknowledgement of the value of self help and employment. Also, from a traditional shoe-string, self help perspective, they are generously funded and resourced. While members and staff are struggling, they clearly have the opportunity to learn skills, acquire new knowledge and participate in their communities in ways that have previously been denied.

The Ontario Psychiatric Survivors Alliance

The sorts of tensions and criticisms sparked by CSDI were nowhere more evident than in the provincial organization it funded, the Ontario Psychiatric Survivors Alliance (OPSA). OPSA had a tumultuous and short-lived existence. What exactly happened is hard to determine because consumers and survivors are not terribly comfortable talking about the subject. However, there are some basic facts that are known. An embryonic

Steering Committee was struck as a result of the 1989 Our Turn conference that Adele Rosenbloom and Dave Stewart spoke of at the beginning of this chapter. When CSDI came into being, this group asked for approximately $800,000 and received slightly more than half that amount, $473,498, to develop an umbrella consumer and survivor organization to which all the other, smaller CSDI projects could belong. "We got big bucks," announced the OPSA newsletter in September of 1991. These were "heady days," says Dave Stewart.

However, trouble was not long in developing. One of the first battles was over the distinction between consumer and survivor. Initially, the organization decided that "only psychiatric survivors could vote but anyone who agrees with what we want to do is welcome to join" (OPSAnews, June, 1991, p. 1). Consumers, who were perceived to be less radical, were not welcome. CSDI, as the arm of the Ministry of Health which oversaw the terms of OPSA's funding, objected, believing that a provincial organization had to be as inclusive in its membership as possible. Some respondents, also, were uncomfortable with OPSA's all-survivor stance. John says, "OPSA asked me whether I was a consumer or a survivor and I refused to answer." Others agreed, feeling that the intense and emotional consumer versus survivor debate echoed the dehumanizing aspects of psychiatric power which members were trying to escape.

> They were polarized. Consumer was defined as someone who thinks everything is fine. You're not aware of any power imbalance and a survivor is the opposite extreme. And most people fall somewhere in between. It was just like labelling someone with mental illness. Like, what's the difference between a psychiatric diagnosis and asking

> someone to fit a strict set of guidelines like OPSA was? It's all the same to me.

M. adds that a kind of grading of misery was also part of the hurtful dynamics.

> There were a number of hierarchies that developed, all of which were dependent upon the degree to which one had suffered, ranging from how poor one's housing was to how marginalized one's employment, or unemployment, through whether one had been on the back wards or really been through the fires and been incarcerated in the Oak Ridge facility at Penetanguishene. The credentials for *real* survivor status became complex indeed.

Jennifer Chambers explains what happened next.

> We came together because of our common experience of oppression and we were all united initially and then things started to happen like someone taking on the position of leadership. And that started to echo in people the feelings towards authority -- authority that they had been hurt by. On the other hand, people who were in the leadership roles felt isolated and criticized. Anyone in a prominent position who's accomplishing things tends to be the focus of attack. That's throughout society, for whatever reason. The more powerless people have been, the more likely they are to have anger against authority figures and the more likely you are to get reamed if you are one of those authority figures. But the survivor movement is probably worse than any other group I've been in. I think it's because, the worse people are treated, the worse they behave to each other. We also tend not to be as afraid of each other as we are of the professionals.

Adele Rosenbloom, as a former Board member, describes what it was like to be one of OPSA's "authority figures."

> I went to an event and one guy came up to me and spit in my face. Unreal! He spit in my face and said, "I absolutely hate you and everything you stand for." And I had never met this person before in my life. Another women came up to me and she started screaming at me and I thought this was just insane. I was spending twenty hours a week working on OPSA stuff at home, in addition to a full time job and a child. My phone would ring off the hook with people who were calling

> to complain about things that supposedly I had said that I did not say or that got twisted around. It was ridiculous. There's this real problem with power and perceived power. I guess people have been put down for so long, have internalized that kind of oppression and they need a scapegoat. They need someone to strike out at and it's easier to strike out at one of their own.

Hugh Tapping felt that there was an intolerable level of tension between the OPSA staff and the Board of Directors.

> I ended up leaving and didn't come back for months. It was because of the coordinators' vicious, nasty, just-go-for-the-jugular attacks when I asked for information. An honest answer may have shown that they were just a little late in getting things done but... OPSA went through four treasurers and every time a treasurer quit, the whole Board of Directors quit too.

Marilyn Nearing refers to this kind of infighting as cannibalism.

> Cannibalism in the movement is alive and well. I see that it's about power. And the first thing you do when you grab some power is run with it. That's exactly what I did when I first got in the consumer movement. After having made some really major errors and having them reflected back to me *rather strongly* -- oh, but of course for my own good -- I learned. After being a survivor of sexual abuse -- this type of abuse was a piece of cake.

But it was not a piece of cake for many respondents. Dave Stewart says, "It cost me to be in the middle of organizational over-throws. As politically alert and knowledgeable as I feel I am at times, being faced with these kinds of politics on a personal level threw me for a loop." M. says, "If you could only keep the power and the money separate but you can't. As soon as somebody gets a job, it sets them apart. They have the money and the others don't."

Eventually, amidst ongoing acrimony, a failure to develop a functional Board of Directors, the public resignation of its own staff, and rumours of financial irregularities, CSDI took the difficult step and recommended that the government withdraw funding. Marnie Shepherd, as a survivor and as a staff person at CSDI, was in a particularly awkward position.

> I guess hindsight's always wonderful because then you can make everything perfect. I was on the phone with someone the other day who had been involved in OPSA and she said, "I confessed to one of the former coordinators that I talked to you and so now they know that I'm the one that caused them to lose their funding." I said, "You didn't cause them to lose their funding." And I said, "Some days I think I didn't do enough." So there's this whole body of people that think they have responsibility for it.
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> Adele says,
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> We had so many opportunities. We had so much money! This wonderful organization that we'd put together from the ground up and we blew it. We really blew it. A lot of it was as a result of the personalities that were involved at the time but, in retrospect, I shouldn't have backed down. I should have maintained a much stronger position but there was no support so I was in it on my own.
>
> Hugh adds,
>
> We fucked up. Every last person involved. Whether they kept their mouth shut or didn't or whether, like in my case, they didn't keep at it. It's the most cruel thing there is to raise people's hopes and expectations and then just not deliver but we did that. People make mistakes and in OPSA, people made mistakes. There was just too much too fast, in view of the brain trust. Like, after the organization starves for two and a half years, the money finally comes and it comes in buckets but there were strings attached and we couldn't deal with it.

Some respondents were careful to point out that what happened at OPSA is not unique in the mental health field. Professionally-run organizations have problems too. Walter Osoka says, "There have been governments that have failed. Lots of organizations have failed. As a matter of fact, there are certain professional organizations that haven't failed, but they should have." Jennifer Chambers adds,

> I'm sick of hearing about the demise of OPSA. I think people's analysis of it is shallow and fragmented and lacking in compassion in all directions. It needs to be analyzed more in terms of a systems failure – Board-staff conflict is not just a consumer/survivor problem. And then you add the reality that survivors' lives are often emptier than others so that makes the strife all the more difficult. Both the Board and the staff were putting so much into it, but when there's internal dissension on top of that, it's too much for anyone to deal with.

Marilyn Nearing concludes,

> The easiest thing for society to say is, "See, we gave them a chance and they failed." I think every mistake the consumer movement makes is going to be held against it. Society isn't trained to look at the gains made. If they were, I think there would be a chance, but I have the funny feeling that there have been enough failures that there's a growing prejudice out there against all the CSDI projects.

While respondents have a number of explanations for the failure of OPSA, most agree that the real problem at the bottom of it all was power. When offered the opportunity to develop their own organization which was clearly intended to provide members with an environment devoid of the harmful power dynamics that characterize the mental health system, respondents were horrified to find that they and their peers seemed inexorably to recapitulate all the ills they so despised. Power as dominance became the enemy-within as members fought each other and their own leaders. The leaders, in their turn, became isolated, angry and burnt out. In specific cases, it appears that members' allegations of wrong doing may have had some basis, in others, it was the perception, rather than the reality that sparked attack. Simmel (in Levin, 1971) argues, like many respondents, that the extremes of oppression drive people apart rather than link them in solidarity. Indeed, Adele says, "it's easier to strike out at one of our own."

Janeway (1980) asks, "How often, in our time, have we not watched the dedicated efforts of some group, struggling to free themselves from oppression, and then witnessed the rebels grow obsessed by the need to hang on to the power they used for their own liberation by setting up institutions that enforce their rule over others" (p. 88). Marilyn Nearing would agree. She believes that consumers and survivors often misuse their new-found power. She says, "An elitist group of consumers can be just as detrimental as the professionals. It's not about taking power. It's about letting it flow down."

Certainly, it was my impression during the research interviews that the failure of OPSA represented a deep wound which respondents felt personally, whether they had been closely involved or not. It also seemed to represent a public shame when, as Marilyn believes, so many people were waiting and watching for just such a debacle to occur. Jennifer Chambers confirms Marilyn's feelings. "The professionals tend to make much out of any dispute among survivors." One of the major strengths of mental health professionals is that they stick together, Jennifer Chambers acknowledges. She adds, "It's a moral weakness, of course, but in terms of maintaining power, it's definitely a strength."

One of the primary tasks of effective protest, after the identification of sources of mistrust and the collective sharing of grievances, is to develop an organizational structure that will nurture and sustain leadership, rally the membership and focus their once disparate energies (Janeway, 1980). The failure of OPSA may, in part, explain the inability of this study's respondents to see that consumers and survivors have achieved victories. Without a visible centre, a movement is in real danger of fragmenting, principally because its members, committed and individually effective though they may be, are unable to capture their successes for the development of a shared history and instead, experience each gain as an isolated and fragile moment which must forever be reinvented.

In conclusion

For centuries, mental patients have been deemed society's "throw aways." In the early 1990s, the Ontario government set up a fund which would promote the formation of consumer and survivor organizations all over the province. In doing so, it assigned a series of complex roles to people who are stereotypically thought of as unmotivated and incompetent. The government also insisted that professionals involve consumers and survivors in all aspects of planning, developing, delivering and evaluating mental health services, elevating their endorsement to that of a legitimizing political symbol (Boudreau, 1990). In fact, consumers' and survivors' nascent political views appear to mesh well with the government's need to restrict mental health care spending through down-sizing and reallocation. However, their new-found popularity, welcome though it initially may have been, did not come without a cost. The seductive call to get involved, coupled with the need to develop their own organizations, left them feeling "spread way too thin." Indeed, it could be argued that flourishing self help organizations may, in fact, be a necessary *precursor* to effective political action, principally because they allow potential movement members to develop a sense of comfort with one another in the relative safety of equal power relationships. When both demands, creating self help organizations *and* developing a political action agenda, are visited upon a group simultaneously, neither can get the attention it deserves, placing both in jeopardy. Certainly, in this case, serious problems are evident. Potential leaders were lost to the new burden of administrative tasks or, more disturbingly, to the pain of vitriolic attacks as organization members grappled with the presence of power perceived as dominance within their own ranks. The development of a collective identity was interrupted by factional wrangling. And in the midst of these many difficulties, the failure of their flagship organization left consumers and survivors without a sound, provincially recognized home base to shelter them while they privately gave birth to a healthy and strong sense of solidarity.

CHAPTER 9

PARTNERSHIP

Janeway (1980) states that one of the signs of a vigorous government is its capacity to include those it governs in its plans. The power contract works badly when the powerful isolate themselves from their constituents and lose touch with their problems and concerns. Wise governments are attuned to any signs of an escalation in dissatisfaction among the populace and judge accurately when dissent can no longer be ignored. In Ontario, growing fiscal concerns, combined with a variety of criticisms aimed at Medicare have meant that unpopular changes in citizens' most beloved social program -- publicly funded health care -- seemed inevitable. In the mental health sector, a policy of partnership evolved out of the Framework for Support model (Trainor & Church, 1984) and was expressed practically as the recruitment of hundreds of consumers, psychiatric survivors and other "stakeholders" for involvement in a province-wide planning exercise that resulted from the Graham Report and was reinforced by the publication of Putting People First. This apparently sudden elevation of ex-mental patients to the status of the government's partners could be interpreted as heralding a new form of power contract, one which emphasizes the views of service recipients over that of the government's traditional partners, psychiatrists and other mental health professionals. In fact, given that doctors, psychiatrists and health care workers interpreted mental health reform as a blueprint for job-loss, consumers and survivors, with their generally anti-institution and anti-psychiatry views, were among the few groups that could be counted upon to support the government's proposed changes. The invitation to participate in mental health reform, as well as many other aspects of the mental health system, placed consumers and survivors in a position of influence which is unprecedented in history, yet this study's respondents have a difficult time acknowledging their victories. One reason may be that consumers and survivors appear to talk about *how* the mental health system operates while government policy is much more focused on *what* and *how much* -- a qualitative versus a quantitative agenda that signals the potential for a collision of intentions.

In this chapter, I begin with an encapsulated review of how respondents' view power as it has been expressed through their relationships with mental health professionals, and with themselves, as they struggled to form their own government-funded advocacy and self help groups. I follow with a discussion of both the threat and the promise of partnership as assessed against the theoretical context of the study. Respondents then offer their opinions of this new relationship. Predictably, problems have arisen and I examine how they define and explain the difficulties. In addition, respondents talk about an array of personal costs experienced as a result of participation. However, they also list substantial benefits and I talk with them about what these advantages are and why they are important. Next, respondents answer the third question of the study, how do consumers and survivors define their relationship to government given that it tends to speak of them as its partners. Finally, I ask whether or not they think that this round of mental health reform will work.

Power in the mental health system

When the government formally sanctioned involvement of consumers and survivors in its mental health reform process, it aligned its power with a group that has traditionally been powerless. However, power in our western culture is most often expressed as dominance -- power over rather than power with -- as it can be succinctly described. We have come by this view honestly. Western child rearing practices are based on power relationships that are generally characterized by dominance. As a result, dominance is often the most common power dynamic reproduced in professional helping relationships and, in the case of psychiatry, it is sanctioned by law. Mental health professionals have, relatively speaking, substantial social powers which are backed by legitimizing symbols and a "doing good" ideology. On the other hand, consumers and psychiatric survivors labour under a social shell constructed of negative attributions which devalue them and weigh them down with a sense of powerlessness. Individually, however, all people begin life in parent-child relationships where they are powerless. As they grow into adulthood, they may retain these childhood memories regardless of the reality of the social power of their adult status. The discrepancy between ascribed social power and an internalized sense of powerlessness can mean that powerful people are unable to see themselves as dominating. When consumers and survivors observe professionals, they say that they see people who don't listen, are sometimes cruel, isolate themselves from their own emotional lives and, when push comes to shove, protect their pay checks above all else. When threatened, they stick together and guard their positions. While respondents describe this last characteristic as a moral weakness, they nevertheless recognize it as an effective tool for the maintenance of dominance. In the wake of the inquest that resulted from the Cedar Glen tragedy, ostensibly powerful professionals were paradoxically able to plead powerlessness as a justification for inaction. They were supported in this stance by the findings of a coroner's jury. Most of its recommendations involved strengthening their social shell of power with an extensive set of new laws that could be called upon to guide action in the future, but consumers and survivors ask, can laws make you care?

On the other side of the coin, this study's respondents have lived lives where their internalized sense of powerlessness is entirely congruent with their marginalized status. Elevation to the potentially influential position of partner appears to have done little to erase their experience of themselves as shunned and stigmatized beings. As a result, they are just as critical of themselves as they are of mental health professionals. When they were challenged with developing their own provincial organization (the Ontario Psychiatric Survivors Alliance, OPSA), respondents found themselves engaged in interactions which they characterized as judgemental, emotional, abusive and ultimately ineffective in establishing a sense of solidarity. They did not stick together and, in fact, tended to attack one another more often than their advocacy targets, professionals, government bureaucrats and their respective policies. Power, they said, was at the bottom of it all, turning them into cannibals and tearing their provincial organization apart. Whose fault was it? "We did it to ourselves. We blew it. We fucked up" were the most common replies.

The portrait that respondents paint of both themselves and their version of Other -- mental health professionals -- is not a particularly comfortable one and while it must be emphasized that this is a study that elicits perceptions of reality rather than objective truths, these sorts of negative opinions would tend to be predictive of serious difficulties when consumers, survivors and professionals get together in partnership. Indeed, Church's 1993 study of the community mental health legislative hearings which arose out of the Graham Report described consumers and survivors as threats to the polite formality of the consultation process, as they shouted, wept and called the committee members assholes. On the other hand, professionals sat in stony silence, inwardly seething but clear that good behaviour and proper manners prevented them from yelling back. This vivid picture of the new "partnership" in action points to a power contract in turmoil, but does it herald real and lasting change?

The threat and the promise of partnership

The threat of the partnership agenda for consumers and survivors is, of course, that it is a sham, simply a tactic to affect unpopular quantitative cost-cutting changes in the mental health system by shutting institutions and reallocating some jobs to cheaper community settings while simultaneously duping them into endorsing the same sorts of power dynamics of which they so vociferously complain. In short, the new and improved mental health system will be restructured from a labour perspective but it will still not provide the help it promises. Janeway (1980) would contend that this sort of outcome is highly likely as the maintenance of the status quo is supported through the natural inertia of the power contract. In fact, when change can no longer be avoided, the typical scenario is for established powers to admit but not honestly welcome into their midst a few representatives from the marginalized group in question. The outward message conveyed is "behave like us and you will get on" (p. 238). However, when invaders take this message at face value, they are not likely to get very far at all. In fact, Janeway argues that the invaders may try and fit in all they please but they will still not qualify as bona fide members of the universe of obligation (Gamson, 1995) because the powerful retain exclusive rights over the definition of what is and is not normal. In other words, "normal behaviour will never be accepted as normal" (p. 239) if it emanates from invaders. Indeed, judging what is and is not normal is the basis for the production of psychiatric knowledge and the wider social application of this knowledge proceeds through government policies which guide the operation of the entire mental health system. Thus, an additional threat of the partnership agenda is that it may siphon off the louder, more effective advocates within the consumer and survivor movement with the seductive, but hollow offer of membership in the inner circle of power, effectively robbing it of its leaders while at the same time, putting them to work as pied pipers leading their trusting peers into a willing acceptance of their own oppression.

Conversely, the promise of partnership is its potential to elevate what Foucault (in Kelly [ed.], 1994) calls subjugated knowledge (the everyday experiences and ideas of consumers and survivors) to a valued position which, at present, is exclusively occupied by formally produced and sanctioned academic and professional knowledge. For example, this research demonstrates that respondents have unique first hand knowledge of the mental health system which is often contrary to the professional view. They say that the system and the professionals it employs miss the point. At best, it does nothing at all and at worst, it's misguided intentions (good or otherwise) add to their problems. When respondents asked for help, they expected the experts to provide meaningful, useful and timely assistance because that's what they're paid to do. However, they were "sadly mistaken." Janeway argues that power contracts which fail, do so because the views of the less powerful portion of the equation have been ignored. Giddens (as quoted in Gadacz, 1994) agrees. He believes that the more opportunities there are for dialogue and interaction between the powerful and the powerless, the greater the possibility that the powerless can have a meaningful influence. Thus, the participation of consumers and survivors in all manner of activities related to the management of the mental health system holds the promise of a more functional power contract, one where both academic and experiential knowledge is respected, producing a mental health system that works.

The problems with partnership

Judi Chamberlin (1978) believes that self help is the path to liberation for consumers and survivors. In fact, she warns against the invasion of even well-meaning professionals into such organizations because they tend to influence disproportionately the goals and objectives of the membership, often diverting energy away from their own liberation agenda towards a more professionally driven one (Chamberlin, 1990). Toffler (1980) believes that "the idea of people taking more responsibility for their own health through self-care alternatives is a "fast rolling new band wagon" (p. 282). In contrast to self help, the concept of participation as envisioned by community-as-supportive-milieu models such as the Framework for Support recasts mental patients as citizens entitled to all the rights that the term implies. In the mental health field, one of the interpretations of "citizen" is a call for partnership.

Gamson (1991) states that vigorous, well-established self help organizations are one of the well-springs from which political activism can flow. In fact, in the previous chapter, respondents concluded that the twin demands of founding self help organizations while, at the same time, responding to an extensive call for partnership left them feeling over-taxed, weary and ineffective. Hugh Tapping believes that, while self help has always been part of ex-mental patients' agenda, partnership is something new and it didn't come from among consumers and survivors.

> I've been in and out of the movement since 1960 -- before it was even called a "movement" -- and this sort of thing never came up. It's a government initiative to which we are responding. There has been a *complete break* between our traditional focus and what's happening now. This whole participation thing -- it sounds great but it's not something that was initiated by us. It was something those deep-think government policy people wanted.

However, Pat Capponi, an extremely high profile psychiatric survivor activist, endorsed participation and, in 1989, received funding to run a leadership facilitation program. While the goal of the program was to identify and develop competent and knowledgeable leadership within the consumer and survivor movement, the clear, underlying message of the curriculum was optimism. Participation was valuable, if enough consumers and survivors could be found and trained in the foreign intricacies of board and committee etiquette. Capponi also argued for the efficacy of a more polite, cooperative approach to advocacy. While identifying the power of anger, she nonetheless taught her participants-in-the-making that an overt display of anger could be counter-productive because "the job is to reach people" and if anger gets in the way of this primary agenda, then "you have failed to do your job" (Church with Capponi, 1991, p. 13).

Indeed, Capponi's efforts suggest that she may well have been aware of what this study's respondents noticed -- it is only a certain type of consumer or survivor that receives an invitation to participate. Patrick Brown says, "Let me put it this way. Professionals probably wouldn't ask me to sit on committees if I didn't have the proper social skills or appropriate hygiene." M. agrees. She says,

> People tend to listen more readily to someone who looks like them. If, however, I was a little less well dressed, a little less articulate, if I hadn't adopted the social graces, if I was really angry and a shit disturber ... it's a partnership as long as we are willing to come on the terms of the professionals.

Another respondent says that, because only a certain kind of consumer is considered "appropriate," its always the same people that show up at the meetings.

> I'm as bad as the next person. I go to all these meetings whenever they ask me and I lay awake at night and think should I opt out of the process or should I not? Then I get there and I'm under attack by the various factions present. Like all the shit that goes with it. And you get to the table and it's always the same people. I've said everything I've had to say and everybody knows my position. It's not like I'm vague or shy. Why don't they ask somebody else? I'm in a fairly privileged position. I have lots to eat. I went to university and it's a long time since I was in the system.

While it appears to respondents that the middle class and well educated members of their group are the preferred partners, they nevertheless report that their opinions are often discounted by mental health professionals and family members causing them to feel "seen" for the purpose of recruitment and "unseen" when they try to speak out. One of the common charges they hear is, "You don't speak for the people who are really sick." This is a statement that raises hackles. Susan Marshall says,

> I got that sort of thing from a really prominent family activist -- right out of her mouth. And we stood up to her as a group and said, "We don't really think it's necessary but if you want, we can bring all our medical documentation and you can read for yourself about our psychotic experiences. We can certainly prove how "ill" we've been." That shut her down.
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> Patrick Brown says,
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> People have said it about me but not in my presence. They wouldn't dare. There were times when I used to eat out of a garbage bin, believe it or not. There are things that I have done that I probably wouldn't dare mention -- things that somebody who's in deep psychosis would do. And there were times when I would sleep twenty hours a day and just get up to go to the bathroom or eat. I'm not obligated to prove that to anybody. I know what it's like to be psychotic. I know what it is to be depressed. I also know what it is to be manic. I know what it is to experience side effects from medication. Whatever you can say about mental illness, I've been there.
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> Marilyn Nearing adds,
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> I get that all the time, especially when dealing with the family groups. They say, 'You were capable and functioning before you got ill but my son will never be able to do that. He'll always need me to protect him and take care of him." Meanwhile we have five people in our group who have been diagnosed with schizophrenia and who have gotten their university degrees. I mean, *forgive me!* With the right support, their son might get there too. I think they've forgotten that we're crazy, not stupid.

These sorts of challenges to consumer and survivor advocacy require allegiance to a somewhat circular argument that begins with the belief that people who are deemed mentally ill are incapable of speaking on their own behalf. Therefore, people who *do* speak out, by this logic, can't have been mentally ill and, consequently, have nothing of value to say about those who are "really sick." This argument also requires an understanding of mental illness as a static, immutable state which, once entered, cannot be exited. Perhaps most telling of all, however, is the demonstration of the "fundamentally incompatible discourses" between consumers, survivors and families (Boudreau & Lambert, 1993, p. 80). Both claim a portion of the truth without a clear path to reconciliation between their opposing views. While Carling (1990) suggests that families are most effective when they stick to their own issues rather than trying to speak on behalf of others, in practice, who speaks for whom can become a muddled and emotional bone of contention.

These family challenges to consumers' and survivors' right to represent their peers lead directly to the question of who among them *hasn't* been invited to become the government's partners. Obviously, answers must be speculative in nature as it's impossible to know for sure who isn't present but there are some hints. First, in the previous chapter, John remarked on the many, many ex-mental patients who are so poor that they are completely consumed by their daily search for the very basics of life, food and shelter. He feels that it's this group that gives the true meaning to the term survivor because, for them, surviving is a full-time job, leaving neither the time nor the energy for political activism. In addition, there are the many patients who remain in institutions and, although there is an effort to involve them in some level of partnership, Jennifer

Chambers believes that they're afraid to speak out because they are so completely dependent on the system that they can't take the risk. On the other hand, perhaps they are satisfied with living in the institution and have little negative to say. Next, there is a group of patients and ex-patients who remain persistently psychotic and whether in an institution or on the street, can no longer be reached no matter what the intention. Finally, there is presumably a group of former patients that have left the system entirely. There is no real way of knowing whether they got the services they wanted and, as a consequence, represent a pool of satisfied customers who might provide a balancing perspective to consumer and survivor critiques or, are they people who just got out, vowing never to place themselves in the hands of professionals again. Either way, they are unavailable for recruitment as partners and their views remain a mystery.

The discussion of who's not present aside, the process of participation for the consumers and survivors who are able or willing to respond to the call for partnership has meant that they are becoming more familiar with the management and administrative workings of the mental health system. Respondents report that they are surprised at what they see. Susan Hardie says,

> At times, I am the most informed at the table. I did extra reading thinking I was way behind. The thing was that these professionals seemed so involved in their work that they didn't take the time to get the most up-to-date information and they were almost looking to me to inform them. Then they would try to find a theory or the book where there was something similar to what I'd said because they couldn't just use an idea that came from a consumer.

Marilyn Nearing adds,

> I'm appalled at some of these professional groups. They blatantly admit that they always broke the rules and now that there are even tougher ones -- I'm speaking of a housing program in this case -- they are now required to have rental agreements with the residents so they make them so complex that no one can understand them and then they tell the residents, who have no resources and no money, to get a lawyer if they don't like it. Because the new rules are a pain in the ass for them, they are determined to make them a pain for consumers too.

She goes on to say,

> I've seen the staff of a psychiatric hospital just whip patients into a frenzy over this mental health reform thing. They've told them that, with shortages and cut-backs, they are likely to be out on the street next week -- discharged from the very home some of them have ever known. They create a dependency and then they take that dependency and they beat the patients over the head with it, using it as a weapon to get their own needs met.

These sorts of incidents are a demonstration of resistance tactics -- unadmirable though they may be -- on the part of rather frightened mental health professionals. Whether they are responding to mental health reform in general, the presence of consumers and survivors in particular, or both, is unclear but they represent evidence of a change in the status quo. In addition, such insights, if used to advantage, could become grist for the advocacy mill. However, respondents seemed not to interpret these events as indicative of the vulnerability of their "enemy" and instead, tend to see them only as further evidence that the powerful are prone to betraying their trust.

The personal costs

Respondents pointed out that the partnership agenda has increased the level of complexity in their relationships with professionals and this has, in itself, become a stressor. For example, consumers and survivors are expected to debate hot topics with admitting psychiatrists who sit next to them at Ministry Task forces but who have in the past, or may in the future commit them for involuntary treatment. I, myself, have experienced finishing an intense therapy session with a client in the morning only to meet the same person an hour or two later in the role of activist at a committee meeting where neither of us knew the other had been invited. These are complicated relationships to negotiate for everyone involved, compromising both the goals of respectful clinical treatment and balanced planning exercises. They also point to the presence of new and unpredictable undulations in the traditional power relations between professionals and patients, with both groups seemingly trying their best to find their balance as they sail turbulent and uncharted waters.

In addition to the stress of negotiating relational complexities, respondents also identified other personal costs which they said they were just beginning to recognize. For example, Angela Browne, writing in the OPSAnews (April, 1992) points out that most consumers and psychiatric survivors live in poverty even if some of them are educated, articulate and in other ways indistinguishable from their mental health professional partners. Susan Hardie describes the effect this discrepancy in economic status had on her.

> We had a committee that worked well together – well, we seemed to be equals. At the end of our work, we had a celebration but when I went to the place for the party, I felt really uncomfortable. I couldn't have afforded even *one* of the pieces of the furniture in the room. I was just totally overwhelmed by the whole experience and the professionals just couldn't understand the difference. I guess the thing was that they denied that it had such an impact on me. All I ask is just acknowledge that it has an effect and then I can stay in there and work, but don't pretend it doesn't

matter.

Another cost respondents identified was the level of energy required to keep going, day after day, when they felt there were no obvious, or at least satisfactory results to lift their spirits. Hugh says, "For three years I've worked from within the system to bring about some change but I haven't gotten anywhere." Donna adds, " One little lesson I've learned is I don't like this. I don't like the responsibility I feel to keep on shoving." Hugh goes on to explain more fully.

> When we're talking about consumers and survivors, we are talking about the walking wounded. This participation thing – well, there are some pretty heavy demands made on us and we're people who, by definition, have fewer social supports and fewer emotional supports like a lack of confidence in our ability carry this thing forward because we don't have a ten year career under our belt and so on. This is a heavy demand coupled with light resources and I'm not just talking about money, I'm talking about a family to go home to, having kids. Kids can keep you going. A lot of us don't have that. Therefore, expect some casualties among us. Plain and simple, as this thing evolves, it's just going to be a given that there's going to be turn over among consumer/survivors, more than anyone would have anticipated.

Jennifer Chambers says,

> All of it has made me more cynical about people than I have ever been before in my life. I've become more aware of what people will do to protect their own interests and that's certainly not been pleasant. I'd say that I like people less than I did before. That's hard. And you hardly ever have pleasant, caring situations when you're doing advocacy – that's another hard part. The easy part is I get to at least say how I see it, even if no one is listening.

Jennifer Reid concludes,

> It takes away from my personal life. It has destroyed relationships because the person I was involved with didn't understand why I was

> working so hard. It destroyed my health -- but it didn't destroy me mentally and I thought it would. After the first year, I figured that if I hadn't gone crazy, I was never going crazy. So it takes away from me physically, emotionally and spiritually, but I haven't gone crazy.

These sorts of personal costs point to the price of advocacy when conducted in isolation. Each speaker soldiers on but without the comfort of a home base to which he or she can return, bringing tales of victory, small and large, for celebration and preservation in group mythology. As a result, successes are lost and life as a political activist truly becomes a Sisyphian struggle.

Being used

Some respondents said that they have the distinct feeling that they are being used. Hugh Tapping says, "There are professionals out there who talk about listening to us survivors but they only do that to get funding." Marilyn Nearing adds,

> I've seen a lot of professionals cultivating their own little group of consumers as a sort of advertising corps because they've gotten the message through mental health reform that they have to have consumers participating in their agencies and programs. They've gotten the message but they haven't gotten the *meaning*. Among ourselves we often say, "Why don't they just cut the crap." We can tell the difference between a professional who means it and one who's just using the language.

Susan Hardie adds, "I hate to use the term used, but I believe that I've allowed myself to be used because what I really want to do is to educate people." In fact, M. believes that many consumers and survivors have a special vulnerability to the invitations they are receiving from mental health professionals and government bureaucrats. She says, "For many of us, it's the first time anyone has ever paid attention to us." Marilyn Nearing adds,

> One of the mistakes I made was that I thought I had "made it." I thought I had become a successful consumer when I found that I fit in and was accepted by the professionals. And then I realized that they weren't listening to me. It took a different degree of wellness for me to see that but now, I take great joy in being more controversial and not leaving everyone feeling cushy.
>
> Jennifer Chambers says,
>
> Consumer/survivor participation has been coopted because people are getting paid to participate. Sometimes people settle for just being allowed to be there. For example, we have someone who's on a lot of hospital committees and he says, "I don't want them to know my real point of view because it's my job to be on these committees. If the administration gets angry at me, I'll be out of a job." There's never a recognition that he's there to represent what consumer/survivors want. On the other hand, people need money. Everyone else present is paid. We should be paid too, but there should be some way of protecting us from losing our positions and the money if we take a strong oppositional stand.

This last comment points out an important change in the mechanics of consumer and survivor participation that has developed over time. During the optimistic consultation process that spawned the Graham Report (1988), consumers and survivors reported that they "had absolutely nothing to lose and everything to gain" by participating loudly and vociferously in meetings (Church, 1993, p. 218). The reason given for this assertion was that they had no jobs to protect, unlike their more cautious bureaucratic and mental health professional adversaries and, as a result, felt no obligation to contain their emotions or edit their remarks. However, today, in recognition of the fact that it costs money to attend meetings, it has become common practice to compensate consumer and survivor participants with honoraria that can range from bus tickets to $10 or $20 per meeting. For people who typically live in poverty, $20 is an important sum. It can also be doubled, tripled or quadrupled monthly, depending on the number of meetings one has been invited to attend. In addition, because it is officially defined as an "honorarium," it constitutes an anomaly that slides by a particularly rigid social assistance rule whereby recipients must report any money earned during the month so that an equal amount may be deducted from their check. These factors have combined to place consumers and survivors in a position where now, they too have something to lose.

In a more general discussion of participation, many respondents said that they didn't know exactly what was going on with all these meetings but whatever it was, the one thing it wasn't, was partnership. Sue Goodwin says,

> They have their cars and their jobs and that's never, and I mean, NEVER going to be my life. This isn't going to work until they walk through my life for a few weeks and see what it's like. I could offer some "input," as they call it, on *that* subject.
>
> John adds,
>
> The government still has all the resources and we're isolated without much information at all so I don't see how you can call it a partnership.
>
> Marg Oswin,
>
> I don't think such a thing is possible until we're regarded as experts in our own right.
>
> M.
>
> The Minister of Health doesn't have any idea what a partnership means. I hold out some hope for one or two of the bureaucrats who are further down the echelon. They seem to have good intentions. And some professionals mean it. Others believe in it only if they can maintain control.

These statements assume a particular definition of partnership based on the idea that it can exist only among equals or near equals. However, Janeway (1980) assumes no such thing and neither, I would argue, does the Ontario government, although it might be criticized for using the rhetoric of partnership to describe what is, in essence, a power contract. Janeway also believes that fears of being used are groundless if, as is the case with the consumer and survivor movement, the powerful have been persuaded to use members' ideas, thereby refreshing and invigorating the power contract with at least the promise of improved functioning. However, this perspective assumes merely a one-way dialogue between social movements and the dominant powers. Movements, even in their nascent form, must be viewed both as a cause of change -- the government has to react to their presence -- and an effect -- the movement must re-form and adapt itself to the changes made by the those in power (Giddens as cited in Gadacz, 1994). In the situation under study, respondents clearly feel that it is they who are doing all the adapting while the expected governmental changes are not forthcoming. Respondents conclude that it is impossible to have a partnership when the social power of one part of the equation so vastly overwhelms that of the other. Indeed, the reality is that, in most instances, the government retains an inordinate level of control in the lives of its consumer and survivor partners. For example, it issues the social assistance cheques that most depend upon. It funds the housing in which they live. It formulates the laws that call for a suspension of their civil rights under certain conditions. It runs the psychiatric institutions that can hold them against their will. It even funds their own self help and advocacy groups. Given that our society's most common experience of power is dominance, it is perhaps predictable that consumers and survivors would distrust the government's apparent good intentions and worry that they may not be all that they seem. Mental health professionals, in their turn, seem equally mistrustful of mental health reform and consumer and survivor involvement, indicating that the partnership agenda may be casting its proverbial seeds on stony ground.

If it's not partnership, what is it?

When respondents so clearly rejected the term partnership to describe their relationship with government, I substituted "activism" as a way of talking about their activities. However, it is a word with a rather unsatisfactory, distant, even esoteric meaning that was never used spontaneously by respondents. Nevertheless, something about the word struck a chord. Paul Reeve grounded the concept with a clearer definition. He says,

> To be active means to grow. It means to strengthen. It means supporting myself and others in their journey. It is really important for me to speak from the heart around issues of healing and recovery in mental health, mental illness, whatever words you want to use. It's speaking out. It's asking the system and ourselves to respect and honour one another.

Paul's definition agrees with those that are more formally produced. Hooks (1989) defines politicization as first, recognizing the personal experience of exploitation and second, as "understanding the particular structure of domination that has caused it" (p. 107). Activism, on the other hand, is the aspect of politicization that demands that people do something about their situation.

To date, the principal outlet for most respondents' activism has been the occasions when they represent their fellow consumers and survivors on boards, committees and task forces. During these times, they say, as Paul does, that it is their mission to "speak from the heart and tell the truth." Sue Goodwin says,

> I speak from the heart. I don't change. I just speak from the heart wherever I am.
>
> Adele Rosenbloom,
>
> I don't censor my thoughts. I speak out. I guess I just speak from the heart.
>
> Jane Pritchard,
>
> I speak *from* the heart and I speak *to* their hearts about my personal truths and experiences.
>
> Susan Hardie,
>
> I've always gone in there with my heart and I've learned that it's really hard to be on a Board of Directors with your heart. It seems I could use some of the professional distance that they use so that I could protect myself from some of the attacks that happen when I'm so open.

It seems, however, there are other, more personal dimensions to their political activism that respondents wished understood. Jennifer Reid explains,

> The movement has given me a sense of belonging. I'm part Native, part black and I'm adopted. There are no roots for me. The psychiatric survivor movement didn't take me as a lesbian, a radical or a feminist. They took me as a survivor – a survivor who told the truth and who had something to say.

Marg Oswin says,

> It's given me my identity. It gives me a sense of who I am, where I've been. I'm more than just a statement of facts. I'm a real, three-dimensional person. It gives me my strength and power. When I'm speaking with survivors about what we need from each other, it takes a load off my shoulders because I can share with them on a level that I can't share with anybody else. When I'm speaking to people who are not survivors and I'm

> pounding my head on the wall -- *again*, I think, are they just not hearing me? What am I doing here? Many times, I just want to say, well, I've done everything I can so it's time to move on but I find that I see more suffering and I respond.

Marilyn Nearing adds,

> It gives me the most excitement I've had in my life. I no longer wake up in the morning and think, why on God's earth was I born? It gives my purpose in life. It gives me great satisfaction. The other side of it is... it can cost at times but the benefits far outweigh the costs. Sometimes I know that I take on a little more abuse than I need to but I know that I'm well enough to take it. And if I need a break, I'll take it. Of course there's always the public ridicule but that doesn't mean anything to me anymore.

Patrick Brown,

> I think one of the good things is that when you do a deed and can look back and see that it's been implemented, that gives you a good feeling. It's also good to hear nice comments from people. That boosts my ego and my self-esteem. It gives me self-fulfillment. I remember there was a time when I was so bloody depressed and so psychotic that I couldn't contribute anything to society and now that has completely turned around so it has given me an incentive to carry on. It also gives me confirmation that, hey, I'm not such a bad guy after all.

Jane Pritchard,

> It's given me a purpose in life. Everytime I open my mouth there is a purpose. Mind you, it's exhausting. But, it's also energizing because I believe that all those professionals out there need to hear what I have to say whether I have the energy or not.

Although respondents feel that it has not been a partnership that has developed, whatever is going on has also not been a total loss. Dave Stewart says that he's learned a lot.

> It's helped me deal positively with a lot of anger. It has also focused me. It's taught me that I can't be the wild-eyed radical that I used to be. I still tend to get more publicly angry than I should and probably alienate people but I have tried, without selling out, to understand other points of view and I've also tried to figure out ways to get my own point of view

across so that people will hear me. I have also come to appreciate that I'm not going to get everybody sold. I can't believe myself sometimes when I become a bit defensive on behalf of the "establishment." I'm not defending them as much as trying to point out that there are two sides to this, folks. I mean I never thought I'd be doing that. Before, it was polarized. They were "them" and we were "us." It's very complicated. But that's also a positive in that I have gotten off my high horse and realized that not everything that certain people and professions do is negative. There can be, *if done properly*, some positives from certain things in the system.

Susan Marshall adds that she's found a job through her activism and it's extremely important to her.

It's given me so much. It really has. My past history was that I would get a job, do well for a few months and then start the cycle of over-work and then get ill and then I'd either quit or I'd get fired, one of the two. So when I took this job, a similar thing happened. Within a year, I was down again but luckily, I was able to pull out of it. AND I still had the job. I didn't have to hide the reason that I was off work. It freed me, I mean, the job itself, but it's more the whole movement really. It freed me to be open and honest in my life. It's made me financially independent which is really important to me -- not dependent on the system or a husband or.. I'm divorced now. That's another thing it did for me! That's a real bonus -- sad but true.

She goes on to say,

And the people I've met -- it's just fantastic. I can cross the province and know survivors everywhere. Even meeting people who work for the government -- the so-called bureaucrats that I had a real contempt for before. I've worked with some of them who just give and give and give. It's fantastic when you meet people who, at least to my knowledge, aren't survivors, yet they give so much.

Marilyn Nearing agrees. She says,

There are two professionals in our area that I met through my participation as a consumer in the mental health system and I'll tell you, when you get a professional who has a real belief system based on values, when they don't feed into the language of the system or act out of

> political expediency, they can do so much for us.

It appears then that when the personal becomes political, it is in the personal portion of the equation where consumers and survivors see and appreciate gains. It is also in this micro domain where professionals emerge as whole human beings instead of the stereotypes described in Chapter 7. Nevertheless, respondents remained clear that even like-minded professionals are not a part of their movement. Susan Hardie explains,

> It's hard for us to recognize that we have allies -- to trust that these people, although they have professional status, are willing to work with us. The reality is though, we cannot ignore the differences.

Gadacz (1994) says that whenever professionals and consumers interact, whether in direct service situations or at the level of planning and managing, their relationship is a dialectical one, "characterized by both unity and the struggle of opposites" (p. 76). They converge on their desire to have a system that works but diverge on the subject of control. Paul Reeve states,

> As far as I can see, consumers and survivors want autonomy and respect. Autonomy being freedom of choice and the support to make that choice and respect being an understanding that I am both worthy and capable. I don't think we have an agreement that professionals share these values. They also need to be more human. They need to be able to say that they don't know it all. They need to stop being a "treatment" or a "philosophy" and just be human.

While respondents are clear they are not the government's partners, naming themselves as activists appears to have decided appeal, capturing more accurately the nature of their critique, while at the same time, acknowledging their fighting spirit. Activists are independent, honourable and committed. They don't give in and they don't sell out. They are demonstrably separate from the powers they assail. They are the modern day version of warriors, lonely, isolated and rather dispirited as is often the case in this research, but nevertheless, warriors who have discovered their purpose and found their place in the world.

Will mental health reform work?

The publication of the Graham Report represented a period of intense optimism for the consumers and survivors that were present during the consultations that led up to its release. Marg Oswin says, "Those were the glory days when we thought anything was possible." Capponi (1992) agrees. "Everywhere we went ex-patients stood up and described how hopeless their lives had become thanks to poverty, isolation and horrible housing. It was a strong message: Do something!" (p. 208). However, Putting People First made respondents worried. While, as Paul Reeve says, it seems to have been intended as an endorsement of motherhood, apple pie and the flag, all rolled into one, a closer reading exposed some disturbing problems. John explains,

> Putting People First was produced by some people at the Ministry offering their own views about what was needed. I still don't know who wrote it. How did they come up with those service priorities? We would have put consumer and survivor projects at the top because they involve employment. And then we would have chosen housing – you want a decent place to live. And then maybe crisis services to give you some place to turn to if things get bad and then at the bottom, case management. I don't know of any consumers or survivor who said that case management was their biggest priority. What we want is exactly the inverse of what the policy says is important.

> Patrick Brown says,

> In my opinion, they should have done some research to see if any of this will work because nobody knows. The idea might sound good, but who

> knows? It might also be destructive.
>
> Dave Stewart,
>
> Where did they get their figures? I don't think there was any real method involved.
>
> Marnie Shepherd, in exasperation,
>
> The Graham Report came out and there was all this planning that went on and when that was done, then there was Putting People First. I thought, when are they ever going to stop writing papers and actually do something? Let's stop talking about it and get started.

In fact, respondents felt that the only concrete outcome of the seemingly never-ending planning process spawned by the Graham Report and reinforced by Putting People First was the growing sense that the call to partnership had, in fact, pitted consumers and survivors against psychiatrists and the unions that represent hospital workers. Donna says,

> The people who are expected to implement mental health reform are the very people who are threatened with job loss and will do everything they can to fight against change. The government, their boss, has come out with this plan and they have to *act* as if they're behind it but they're really going to sabotage it and there can be no doubt about it.
>
> Marilyn Nearing adds,
>
> Coming on too strong with this sort of policy can cause a backlash. Mental health professionals are really afraid of losing their jobs. It's just pitted two vulnerable groups -- labour and the mentally ill -- against one another, although there are a whole lot of reasons to believe that consumers and survivors are more vulnerable than the labour force.
>
> Jane Pritchard,
>
> There are hundreds, no, thousands of unionized hospital workers who will need jobs and because of the union's strength, they will fight to protect those jobs.

Susan Hardie,

> The major issues are those of the unionized workers, job-loss and re-training. I don't see our issues -- poverty, for example -- coming first at all. It's all about jobs. We stay poor and they benefit from our despair.

Sue Goodwin concludes,

> Honest to God, my only hope is that survivors will be able to grab a chunk of the money and keep making our voices heard.

The idea that the consumer and survivor movement, with its typically anti-institution stance, may be providing government with a utilitarian logic that will serve as a saleable argument for downsizing or closing expensive psychiatric hospitals is, obviously, not at all far-fetched and the present neo-conservative political climate merely supports this belief. The above comments also emphasize respondents' earlier expressed fears that they may become targets for retaliation. The fact that consumer and survivor activism has created an environment where mental health professionals have become afraid could be seen as evidence of a victory, but it is one that respondents feel has a dangerous double edge. While government bureaucrats may seemingly welcome them with open arms at the planning table, they won't be present on the admitting ward to provide protection should their former consumer planning "partner" suffer a breakdown and require hospitalization. Indeed, consumers' and survivors' stories are full of accounts of the small, cruel abuses that can take place on a psychiatric ward regardless of regulatory policies and procedures. They know that all the rules in the world won't protect them if no one is looking.

Such fears are all the more powerful because they encourage disconnection from a calm, rational assessment of probability. While consumer and survivor activists may, indeed, be well known if they reside in small towns or in rural areas, only the most prominent activists have any public profile at all in large urban centres. As a result, it is entirely possible that harried hospital admitting staff and over-worked ward professionals may have no idea of the political activism of their patients. However, the individual activist-turned-patient would know, and the experience of having re-entered in totality, the former powerless role would be all the more humiliating because of the heightened contrast between it and the new-found status conferred by political activity.

An additional source of concern for consumers and survivors is the fact that plans developed at a bureaucratic level are a long, long way from the realities of the direct service interface between professional and patient -- arguably the most salient power contract in the entire mental health system. When the present study began, mental health reform planning had already been underway for six years and respondents were clear that they were beginning to lose faith that the hundreds of documents it had produced would ever be translated into real, observable change.

> Donna,
>
> We've never re-distributed the money in any real way like the politicians promised so there's nothing that's been added to the community. So, we're set up for failure just like in the '70s. We're going to wind up with all the crazies on the street with none of the supports, no housing, no money and they'll be disruptive, they'll be visible, and there will be a big social outcry and then they'll get re-incarcerated in the institutions all over again.
>
> Jane Pritchard,
>
> They're lying through their teeth and they know it. They don't have the money to do what it is that they said they would and they don't tell people that.
>
> Adele Rosenbloom,

> I'm feeling very pessimistic. It's scary. I don't see any real change taking place.

Susan Hardie,

> I know they used the words, "putting people first," but the power imbalances haven't been addressed so I don't see a whole lot changing.

A respondent who prefers anonymity concludes,

> Mental health reform doesn't exist. How is it any different than what we were doing before it all started? What's changed? Well, there are some more services but the power dynamics haven't changed, the underlying ideology of the system hasn't changed. There are just more "things" out there now.

While some respondents feel that Putting People First might possibly have signaled good intentions, they clearly believe that it has become derailed during implementation discussions. One reason may be that plans have tended to focus mostly on quantitative targets such as institutional bed reductions and labour strategies to facilitate either lay-offs or the redeployment of unionized staff to poorer paying community-based jobs. Respondents believe that their qualitative concerns, which concentrate on how the system functions rather than how much it costs, have been lost, while, at the same time, some feel that the only observable result of so-called partnership is to have pitted consumers and survivors against powerful unions who are, indeed, facing a serious threat. Respondents conclude that mental health reform cannot work if the fundamental qualitative issue, how power is used, is not addressed, first in the mental health system as a whole and second, in its key direct service function. Gadacz (1994) states that professionals and consumers have yet to agree on a change in the nature of this extremely important power contract. In this case, consumers and survivors say, "We want autonomy and respect." However, there appears to be no real evidence that professionals have altered their traditional stance which says, "We are the experts and we know best." Finally, adding to the anxiety and frustration, action of any sort has been exceedingly slow in coming. In the process, endless planning has fuelled everyone's fears. Consumers and survivors fear retaliation, psychiatrists fear a loss of power, other professionals fear for their jobs, unions fear the general anti-labour tenor that is evident in some of the plans, families fear an erosion of services and the community mental health sector fears that the promised program enhancements will never arrive.

In such an atmosphere of instability, the professional position is indeed a shaky one. Their power is eroding. The institutions that have employed them are closing and the unions that have protected their jobs are under attack (Armstrong & Armstrong, 1996). However, mental health care is an activity where the primary resource is people. Putting People First (1993) is virtually silent on the issue of its own impact on the people who work in the mental health system. Important employee support measures such as education and training, well-thought out systems for reallocation to community jobs and a strategy to address remuneration differentials are absent. In addition, there are minimal plans[1] to create the community services in which displaced institutional and hospital workers are supposed to be employed. It is no great leap of logic to presume that unhappy, down-trodden and threatened workers are likely to produce an even poorer standard of care than the supposed deficiencies that

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[1] In the Spring of 1995, the then Minister of Health, Ruth Grier, announced a 20 million dollar Community Investment Fund which was to be dispersed in service of beefing up community mental health services prior to down-sizing provincial psychiatric hospitals.

sparked reform in the first place. Further, in the government's desire to contain costs and manage a seemingly out of control system, it has de-emphasized the views and concerns of its traditional partners, psychiatrists and other mental health professionals, in favour of those of consumers and survivors. Throughout the eternal and, it must be noted, enormously expensive planning activity that has so far been the only tangible product arising out of mental health reform, professionals find themselves side by side with consumers and survivors creating policies that may well herald the demise of their own institutions, hospitals and agencies -- manufacturing a do-it-yourself hangman's kit -- as survivor activist Colin Young is rumoured to have said in a show of sympathetic black humour. While the consumer and survivor voice has been an important and virtually absent ingredient in mental health discourse, pitting it against the interests of medicine and labour can hardly improve quality of care in either the short or the long term. In short, mental health professionals seem to have joined the ranks of the disempowered and they appear to have no immediate way out of their dilemma. Government can take the ideological high ground and argue that it is merely acting as a responsible representative of its tax-payers' concerns. In the same vein, consumers and survivors can comfort themselves that they are the champions of a forgotten but essential group that requires vigorous representation no matter whose feelings get hurt. And finally, family members may take the entirely sympathetic stance that it's their loved ones they are fighting for. But mental health professionals, the people relied on to provide the improved care that mental health reform is designing, are embattled on all sides. Consumers, survivors and often family members view them with contempt while their own employers are threatening them with job loss. In the midst of these dynamics, professionals seem to have been assigned the exclusive role of villain. Those who take an advocacy stance on behalf of their patients or clients are seen as using them to advance their own interests while, on the other hand, if they stand up for their own rights as employees, they are viewed as selfish turf-protectors. Thus, while the power relations in the mental health system could be said to have shifted, it would appear that from the professional perspective, as well as from the viewpoint of consumers and survivors, mental health reform isn't working at all.

In conclusion

For respondents, the hope associated with the government's call to partnership was its potential to affect qualitatively the nature of the mental health power contract on both micro and macro levels. Their presence on literally hundreds of Boards of Directors, committees, planning groups and task forces certainly represents a change but they report that many of the same aspects of the dominant power relationship they experienced while patients or clients in direct service settings are reproduced in the macro areas of system planning and management. They feel they are selected because of their middle class backgrounds and education, yet they are attacked because they "don't speak for really sick people." Some say that, despite all the welcoming rhetoric, their ideas are ignored. Many say they feel used, recruited merely as a counter-weight to the power of psychiatrists and unions who are threatened by the government's emphasis on fiscal restraint. In the midst of the turmoil, everyone is afraid and the promise of a reformed, invigorated and functioning mental health system appears to be receding. In fact, respondents, psychiatrists (OPDPS, 1994) and unions (OPSEU, 1991; 1994) seem to be reaching similar conclusions. Mental health reform, as articulated in Putting People First, is an administrative document, concerned mainly with system management and cost-effectiveness, relegating important qualitative concerns such as *how* services will be delivered to a secondary status. A significant missing piece, however, is a solid consumer and survivor advocacy position offered in a strong, clear voice. While there are hints that they embrace a form of liberation ideology, *exactly* what they want as a collectivity may be a question that consumers and survivors, themselves, have yet to answer.

CHAPTER 10

WHAT DO CONSUMERS AND SURVIVORS WANT?

Consumers and psychiatric survivors appear to want qualitative changes in the mental health system -- changes which have to do with a fundamental alteration in the nature of both the macro-level power contract (how the entire mental health system operates) and the micro-level power contract (how professionals help their patients and clients) -- but what, specifically, does that mean? Janeway (1980) believes that a viable social movement must have a creed or an ideology which functions as its legitimizing symbol. Creeds are expressed in a variety of ways. Sometimes they are contained in lengthy mission statements or manifestos. At other times they are reduced to catchy slogans or songs, but no matter what their form, their function is to rally the membership so that they are marching under the same banner. The power of a creed lies in its ability to connect members' emotional commitment to a rational, well-thought out agenda for change. If a rising sense of uneasiness has made the powerful restless and they have come to call, asking "What do you want?, movements benefit if they are ready with a clear answer. For example, the women's movement has rallied around the slogan, "the personal is political." As a creed, it is somewhat curious in that, on one hand, it uses powerful words which denote a strength of purpose while, on the other, it requires a considerable amount of thought and effort to figure out exactly what it means. Nevertheless, it has served as a legitimizing symbol for feminists and, many years after its invention, continues to colour their personal, academic, business and political lives. In a second example, the public has come to understand that, while the physically disabled may want many things, they *demand* accessibility. As a result, they have been hugely successful in pressuring governments, businesses and transportation companies into making costly structural alterations so that people in wheelchairs and the blind can navigate the able-bodied world as independently as possible.

So far, the current expression of the consumer and survivor movement appears not to have been able to settle upon such a clearly defined agenda for change. Hugh Tapping states that the government's present call to partnership constitutes a complete break from what an earlier version of the movement had in mind. This previous ideology seemed to centre around Chamberlin's 1978 call for self help and survivor-run alternative services. Today, with consumers and survivors participating in unprecedented numbers in a wide variety of activities related to all aspects of the mental health system, the development of a coherent ideology has become a more complex task than when they were fewer in number and their activism went virtually unrecognized. One potential reason for their seeming lack of clarity may be the Ontario government's partnership agenda which appears to have diverted them from the task of developing their own ideas for change.

Janeway (1980) argues that the evolution of a movement's ideology is, under the most ideal of circumstances, a difficult task because so many things may be wrong that it's hard to sort out exactly what to concentrate on. Indeed, respondents have remarked upon the difficulty of retaining their focus when so many things need changing. Second, it is the powerful who know how things work and consumers and survivors have had limited access to even the most basic facts and figures so that they can advocate effectively for themselves. John confirms this perception. He says, "We're isolated without much information at all." Finally, in order to create an ideology, movement members must first understand how the powerful function, and, in the light of that knowledge, develop persuasive and compelling counter-arguments which face the difficult task of changing long term, well-established and embedded traditions -- a daunting task which leaves even the strongest movement members frustrated. As Marg Oswin says, "I pound my head on the wall. Is it me or is it them?"

In this chapter, I attempt to find out what it is that consumers and survivors want. First, I begin with the final question of this study, what do consumers and survivors think mental illness is and what do they think should be done about it? This was an important question for me because it harkens back to my first experiences as an inpatient social worker. I had a lot of interest in what respondents would say and I also felt that it might be here, in their answers, that their ideology lay. In fact, I was wrong in this assumption and it is in the second part of the question, what they think should be done about it, where what might be called an embryonic creed is emerging. Thus, I examine both what respondents feel mental health professionals need to do about mental illness and what consumers and survivors need to do. I conclude this chapter with a discussion of what the study's respondents believe their future holds. Will the consumer and survivor movement be successful? And will respondents, as individuals, continue to be a part of it?

It's a chicken or egg thing

Historically, discussions around the etiology of insanity or mental illness have polarized around the age old nature-nurture debate. Is it an inescapable biological fault expressed as a disease or is it socially created, a sane response to an insane world? Treatment responses are also split, physical remedies for the biologically-based proponents and talk therapies for those who believe more in social causality (Pilgrim & Rogers, 1993). Janeway states that we seem doomed to view these sorts of problems in "binary terms" (p. 305). Life divides into black and white, right and wrong, yes and no, and these divisions are based on our view of power as dominance, a view which creates only two ranks within the power contract; the haves and the have nots, the powerful and the powerless, the strong and the weak. Further, these two ranks are often cast in direct opposition to one another, win or lose, harm or be harmed.

The respondents of this study initially reported that they felt that people who call themselves psychiatric survivors typically support the nurture side of the mental illness debate (social causality) while consumers are those who embrace the nature side (biological etiology). In practical terms, respondents, although identifying politically as survivors, reported that they actually lived their lives somewhere in between these nature-nurture explanations, sometimes taking medications and "consuming" services and sometimes not, a precarious balancing act from the perspective of clear-eyed and dedicated advocacy. In fact, the question -- what is mental illness? -- seemed to touch places that were intimate and hard to talk about. Respondents typically paused for some time after I asked it and often remarked, "That's an *interesting* question." Most answers did not come easily. Two respondents had less difficulty than others and answered with a well-thought out, personal philosophy statement which, in Jennifer Chambers' case, seemed to be based on her experiences as a peer counsellor. Jennifer says,

> I think that what happens is that when people are hurt, they develop difficulty in thinking in those areas in which they were hurt. The natural way people heal from the hurt is to express emotion and get loving attention. If we aren't allowed that, we build up more areas in which we have difficulty thinking and that's what ends up being called mental illness. These hidden feelings finally break through and they are considered to be manic or psychotic or you have people who are so successful at keeping themselves shut down, they're diagnosed as clinically depressed. I believe that what people refer to as delusions and psychoses are an attempt of the brain to sort out stressful events symbolically, like dreaming does when we're asleep. I think that it's possible for almost everyone who has a label of mental illness to be much better than they are but there would need to be a lot of love and a lot of attention. It would require widespread societal change because I think changes in child-rearing techniques would be the way to start.

Donna's philosophy seems more closely based on her own personal experience.

> This thing that we've labeled mental illness is really just sadness and discouragement. These feelings have a natural function -- they're a normal response to abnormal situations. But we've got professionals to convince us that there's something wrong with feeling that way and that we need to go out and get help to help alleviate these problems. We're taught that it's not normal instead of embracing our pain and understanding that feeling sad is just as normal as feeling happy. So, we end up with a whole bunch of people saying there's something wrong with the way that we're behaving and medicalizing it so that we have diseases.

Other respondents were more tentative. Susan Marshall says,

> At first I thought that there was no such thing as mental illness. It was a reaction to abuse or trauma -- people's different coping mechanisms. I still think that's a large part of what happens -- a really large part. But I'm starting to be open to the thought that there's something chemical that happens in the brain and respect people's beliefs on that.

> Dave Stewart,
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> *Something's* wrong, that's for sure. It may come out of great trauma or there may be some biological, chemical or physiological maladjustment -- I'm just very skeptical of the term mental illness. I think it has been badly abused and poorly understood.
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> Susan Hardie,
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> I guess it's the oscillation between hope and despair that all of us go through. I will never accept anyone who says it's one hundred percent biological or that it's one hundred percent non-biological. I've seen medication improve some people's lives and I've seen the devastation it creates. I think people have to develop their own understanding of their experience.
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> Paul Reeve concludes,
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> I can create all sorts of chemicals in my body due to my interactions with the world. It's a chicken or egg thing.

Some respondents felt that child abuse was at the bottom of it all. Alice Miller (1981, 1983, 1984) argues that most of our child-rearing practices are potentially damaging and that even those parents who are kind and loving are unconsciously shaming and humiliating their children in ways that harm their tender and developing emotions. From her perspective, overt child abuse is merely the extreme end of a cultural continuum that, as a whole, disrespects and devalues children. The more extensive and violent the abuse, the more emotionally disfigured the child -- and eventually, the adult. Jane Pritchard says,

> I think that so-called mental illness has to do with spirit killing and I believe that for most people it begins in early childhood. If your spirit is killed before you even get going, you don't know how to live, you don't take care of yourself and I don't mean just physically. I mean you don't learn how to nurture yourself and to have a sense of yourself. An abusive childhood causes people to develop different ways of coping that end up

> looking like strange behaviours which are not accepted by society. Yet, these behaviours are perfectly normal to them and are, in fact, what kept them alive, at least in body if not in spirit.
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> Marg Oswin,
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> I was sexually abused when I was a child and that led to other things that eventually put me into the system. If indeed I was depressed, it was associated with a life event and not with a disease of the mind. If people have neurological problems, you can call that an illness but *any* illness is associated with the body, mind, spirit and emotions. What they call mental illness is an emotional dis-ease that is best treated with therapy, not with electric shock.
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> Sue Goodwin,
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> It's abuse, all through your life, starting as a child. You can't be cured of abuse by drowning your mind in drugs that make you forget. You have to take responsibility for yourself but you can only do that once you understand and are helped by talking it through. In my case, talk and talk and talk and talk.
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> Marnie Shepherd,
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> The more consumers and survivors I meet, the more and more I think of the environmental impact. Early on in my understanding of this, I met somebody who had been sexually abused. She is a twin. She was the only sister that was sexually abused by her father. She would tell stories of what he would do and how he would have card parties and bring home the men and it was just awful. I look at her and here she is in her late twenties and I just don't think the day's ever going to come when she's going to think well of herself because there's never going to be an answer. Why did he abuse her and not her twin sister? And I think it's never going to matter how many people tell her it's not her fault, it's never going to go away.

Finally, a few respondents felt that "what is mental illness?" wasn't a question that was worth the bother of answering. Walter Osoka says, "It's many things, loneliness, social pressures, loss of a job or a loved one, lack of support, not fitting in. Pinpointing a definition is a waste of time." Patrick Brown, who says on one hand, "Whatever you can say about mental illness, I've been there," nevertheless, felt stumped by this question. He said, "It's very simple. I don't know."

Chamberlin (1978) states that "mental illness" is the kind of problem that taps into much larger human issues which are often the province of philosophers – what and where is the mind? What are emotions, thoughts, ideas and how are they produced and acted upon? The connection between the mind and the body is, in some quarters, being re-thought or, as some would say, re-established, given the traditional emphasis in medicine on the Cartesian mind-body split. For example, epidemiologists who study the general health of whole populations both historically and in contemporary times, argue that most of our health care policy is based on simple "repair shop" notions of health and illness – when something goes wrong, the offending body part must be isolated and then, fixed or replaced (Evans, 1994). When mind and body are viewed as inter-related and, in fact, defying disentanglement, the polarized nature-nurture debate that characterizes mental health disappears and in its place emerges viewpoints such a those offered by most of this study's respondents – mental illness is a little bit of both. Evans (1994), like respondents, concludes, "genetic and congenital factors are not unimportant but the expression or non-expression of their effects depends on social environment" (p. 20). In fact, this author reports that the most pervasive finding in epidemiological studies of population health is that the less control people have over their lives, the more stress they are under and, as a consequence, the poorer their physical and mental health.

Gil's (1996) theoretical framework which identifies our society as structurally violent hypothesizes that one of the effects of initiating social violence is that it prevents large groups of society's outsiders from meeting even their basic human needs. In light of the above set of epidemiological findings, this sort of endemic violence would create a tremendous effect on health and, by extension, health care costs. In addition, in the specific case of child abuse, van der Kolk (1987, 1994) links trauma to chemical changes in the brain that affect the ability to regulate thoughts and emotions, interpreting scientifically what respondents seem to have understood intuitively -- physical, emotional or sexual abuse produces temporary and perhaps permanent alterations in the functioning of the autonomic and central nervous systems. Further, it has been found that the greatest impairment is experienced by adults who were violently abused very early in life, for long periods of time, by multiple abusers usually including a parental figure (Brown & Finkelhor, 1986; Goff et al, 1991). However, child abuse along with domestic violence and rape are only a few examples of the sorts of experiences that thwart human potential. Evans (1994) points to other problems such as poverty, often concomitant with poor housing, inadequate nutrition and an inability to achieve an education, as predictive of poor health. In addition, Ontario is a favored destination of immigrants and refugees who bring with them a unique set of stressors related to lack of employment, an inability to speak either of Canada's official languages, the loss of friends and family, and racism. Some are refugees who have experienced rape, torture, and confinement in a concentration camp or prison. Women, children and old people appear to suffer the most (Durbin & Sondhu, 1992, p. 6). Finally, First Nations people experience four times the suicide rate of non-Native Ontarians and are known to struggle with inferior housing, poverty, racism, substance abuse problems, unemployment, child abuse and violence (Graham

Report, 1988). All of these social problems have vast implications for both physical and mental health.

Also, Evans & Stoddart (1994) argue that these sources of stress, and many others which may be rooted in idiosyncratic experience, are the kinds of things that place strain on the human organism which, in turn, leads to an experience of suffering. However, whether or not people define their discomfort as a health concern depends first, on their expectations of what the health care system can deliver and second, on the ready availability of services. In the case of this study, respondents reported that they struggled sometimes for long periods of time before they turned to the mental health system hoping that the experts would "fix it." Indeed, the express purpose of medicine is to re-define patients' experiences of suffering as disease (Evans & Stoddart, 1994). This translation process -- from dis-ease to disease, as respondent Marg Oswin calls it -- is then supposed to be accompanied by a known treatment protocol and a prediction of outcome. It appears that it is at this point where respondents felt the system began to let them down. Help, as they defined it, was not forthcoming and instead, many encountered what they viewed as the violence of psychiatric treatment, particularly involuntary commitment and forced treatment.

What needs to change

In Chapter 6, respondents discussed what they had hoped the mental health system would deliver when they approached it for help. In terms of this study's theoretical context, respondents expected a power contract that was based on self-empowerment and liberating power relations -- nurturance, encouragement, support and guidance, all aimed at the eventual goal of liberation, a time when patients could once again stand on their own two feet. Jennifer Reid says, "I believed that they would fix things so that I would get better... be able to go out into society." Patrick Brown adds,

> We need empathy. We want to hear, "Hey, you can make it!" If you place your confidence in people, I think you'd get the kind of results that would blow you away. Most survivors don't have confidence and that's what they need.
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> Paul Reeve advises,
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> Ask us what we need. Don't tell us. It's wonderful to give a person who's in pain some responsibility -- support too -- but responsibility for choosing their own direction. That's empowering and is, in itself, part of the recovery process.
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> Susan Hardie,
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> It's not about theories and textbooks. It's about simple things. Just by giving a person the time of day, we're telling them they are of value and that's not taught in school. You have to allow people to sense that you really believe in them and you believe in their abilities. There are some real, real issues and you don't have to be a consumer to see that they are important -- like poverty and housing. If a person is discharged from hospital with all they own packed into a garbage bag -- well, how stable are you going to be living out of a garbage bag? Like, simple, simple issues that need to be addressed. And isolation. I would say that the people in the *most* need are those that are so isolated. I was there -- I was one of them. And you have to be patient and you have to just be there with a message of, "Yes, I care." And it takes an extended period of time and it isn't about taking control of someone's life or using power. It's about very basic people skills and I don't think we concentrate at all on these things.
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> Jennifer Chambers,
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> There need to be places where people can go -- places of real healing, loving, supportive places where people would be allowed to show

> emotion. Almost everyone in society is afraid of emotions -- especially mental health professionals. It's not cool for people to be sobbing endlessly but that's what many of us need to do.

> An anonymous respondent,

> People's problems are individual and that's where the failure is. We have a system. And then we have individuals. We have models. And then we have individuals. A system or a model doesn't take into account people's differences.

> Concluding the discussion, Susan Hardie adds an addendum to her statement above,

> When I first started in this movement, I had never used the terms social control or oppression. Those words were just *so hard* to speak, but when I really began to look at what they meant and what function the mental health system has in our lives, I think we, as a society, have to ask ourselves, what role are we asking psychiatrists and other mental health professionals to play? Is it social control or is it health care? I think we are getting to the point where there are some real ethical questions we need to address but people are still beating around the bush -- not looking at the real issues and not discussing them openly.

In discussing some of the ethical questions that Susan speaks of, respondents named a number of concerns, beginning with the central question of involuntary treatment.

> Walter Osoka,

> I don't think storing up people in institutions is the way to do it. How would someone with diabetes do if they were out on the streets without a place to go, without friends -- where someone can put them in a room, lock it up and take away their basic right to say yes or no. How do you think they would fare?

> Susan Marshall,

> If it were up to me, I'd take away the power psychiatrists have to lock us up. Maybe somebody has to have it somewhere but I know that times when it is required are few and far between. I think a really big part is that

> we don't do a whole lot to make it safe for people to come out and admit they need help.

A second ethical question for respondents is the powerful role that pharmaceutical companies play in the system.

> Sue Goodwin,
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> The government always says it's too expensive to do the things that we want done. In fact, I think it would be *cheaper*. It costs billions to lock people up and drug them. They drug us in the institutions. They drug us in the jails. They can even drug us in our communities. But it's not cheaper in the long run. The government pays through OHIP bills and we pay through our hearts. Big time.
>
> Paul Reeve,
>
> Pharmaceutical companies don't make money off self help groups. They don't make money off anyone but the medical profession.

A third issue was work. Putting People First fails even to mention employment which was an absolutely central concern for many respondents.

> John,
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> People need jobs -- their own income so they can be really, truly independent. The way it is now, people get out of hospital and they're on social assistance. Having your own income means you're more likely to recover and be less dependent on all those community supports that they're talking about under mental health reform.
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> Walter Osoka,
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> Someone once said, "It's amazing how somebody's emotional health gets better when they have some money and food, a roof over their heads and some friends."

Respondents also felt that the important issue of child abuse seems to receive very little attention.

> Marilyn Nearing,
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> I'm adamant that if professionals understood the abuse that underlies so-called mental illness, we'd have it whipped.

The global term that respondents most often used to describe what they wanted was support, "emotional and economic support," says Marilyn Nearing. Evans (1994) states that "a supportive environment helps us bear heavier loads without breaking" (p. 22). Support, as defined by this study's respondents is two fold. First, there are the intangible, emotional components associated with the kind of support offered by friends, family, and community which, ideally, includes respect, empathy, interest, love, encouragement, acceptance, guidance, understanding, patience, faith in one's capabilities, a shoulder to cry on, a space to express difficult emotions, a listening ear, a place to belong and a reason to live, to name some of the needs expressed by respondents. A second component of support is its more tangible, economic aspect, sometimes called broader health determinants (Evans, Barer & Marmor, 1994); housing, income, decent food, safe communities, an education and a job. Of course, this list of needs is all too familiar given that it includes exactly the same sorts of things my own former patients said that they wanted. However, as professionals, I and my colleagues were unable to provide these sorts of supports and, instead, translated patients' expression of suffering into a psychiatric diagnosis which, in turn, led to things like hospitalization, medication and ECT, marginalization, poverty, unsafe and inferior housing, violence or many of the other hard realities that typified patients' lives. In fact, respondents repeatedly charge that professionals miss the point, fail to help and actually make their problems worse through the trauma of involuntary treatment and the stigma of psychiatric diagnosis.

When framed in this fashion, discussion of mental patients' needs usually elicits a countervailing argument which centres on the prevalence of violence among them. How do families, mental health professionals and community members support someone when they feel terrorized by them? As discussed in Chapter 4, families have real fears for their own safety. Indeed, they have been found to be the most common targets of violence by psychiatric patients. In addition, violent incidents are increasing among inpatients in psychiatric facilities and even though it has been found that it is often only a small number of patients who are perpetrating these acts, and usually those with concommitant substance abuse problems, it nevertheless remains an important concern (Arboleda-Florez, Holley & Crisanti, 1996). Indeed, it has been my own experience that even one violent patient on an inpatient ward can create fear and chaos. The same must be so for families who have experienced violence at the hands of their relative. While extensive research proves over and over again that violence is, relatively speaking, uncommon among mental patients, it is the saliency of the issue that skews thinking. Violence, as a component in the power contract, immediately shifts the power relationship and can colour societal responses towards an entire marginalized and, in the main, powerless group (Gil, 1996). I discussed this issue with some of the study's respondents, seeking concrete examples of how their philosophy of support would work in the face of the threat of violence. Jennifer Chambers, as staff to the Patient Council at

Queen Street Mental Health Centre, works in a hospital environment where violence is a substantial presence. She has, herself, been assaulted twice while at work. She says,

> To work here, I think you have to deliberately numb yourself. It's physically dangerous. I feel for staff who are dealing with people who are at the point in their lives when they are violent. But I believe the solution is not to build more seclusion rooms and, instead, allow people an outlet for their anger -- more emotional support and more people who will listen. Often, all people want is attention and violence is the only way they know how to get it. People who have been violent or have been assaulted need to be talked to -- listened to, more likely, and in detail, to find out what's going on and what would help it not to happen again. It seems such a fundamental thing to do. But they don't do it, partly because they refuse to look at the contributions of the staff to the violent incidents. Staff don't contribute *always*. Sometimes it's just inheriting anger towards somebody else. But, still, there are times when staff are cruel and callous. Times when people get restrained because they are rude and loud, things that piss the staff off but which aren't legally supposed to result in restraint like criticizing the staff or not taking drugs. In order for things to change, there would have to be some difficult choices made about how things are done.

Marilyn Nearing described an incident that occurred in the same hospital where she illustrates how she used her own power to avert what may have escalated into a violent incident.

> A couple of springs ago, I went to a conference at Queen Street and a patient came up to me in the cafeteria thinking I was a professional because I had a badge on. She started screaming at me that somebody had stolen her shoes and that no one cared. I was uncomfortable and I tried to tell her that I was a consumer and the more I tried to tell her that, the more she yelled. And then I realized that what I was doing was defending myself instead of listening to her so I finally sat down and said, "How did you lose your shoes?" And the calmness that came over her after about ten minutes -- because we were talking about her issue. I was no longer defending myself and worrying about my position. Eventually she said, "Oh well, maybe they're in my room." And the anger was diffused. I thought to myself, it would have been *so easy* if I had the power to tie her up and medicate her because she was obnoxious and

> inappropriate and all those things that so many of us are at times. But all she wanted was someone to listen to her.

The sort of interaction that Marilyn describes seems to call for a basic, common sense response but the reality is that it is not easy to stay calm and caring in the face of the threat of violence. In fact, Jennifer's suggestions and Marilyn's example are illustrative of the fundamental shift in thinking that would have to occur in the present mental health system and, indeed, in society as a whole if a violent repressive social response were no longer an accepted course of action (Gil, 1996).

Monahan and Arnold (1996) argue that the erroneous public view that mental illness and violence are inextricably linked drives the production of our public policies and our laws. A presumption of dangerousness is what underlies psychiatrists' power to detain and treat patients against their will. Involuntary treatment is a point of major disagreement between survivor activists, families and many mental health professionals (Carling, 1994). This author goes on to say that "the problem is compounded by a virtual absence of basic discussion within the field as to when involuntary interventions are legitimate or helpful, and by an absence of research on consumers' experience of involuntary interventions and on their long-term effect" (p. 84). Boudreau and Lambert (1993) state that, paradoxically, both sides of the argument invoke the concept of autonomy as justification for their position. The pro side contends that autonomy and freedom are grounded in compliance with society's rules and regulations. Psychiatric treatment is valued because it is thought to prevent the loss of autonomy through a recurrence of an episode of psychosis. Forcing patients to comply with treatment is unfortunate, in the short term, but in the long term, it is good for them because it is believed to ensure their eventual freedom.

The con side of the argument says that forced treatment is an expression of dominance and a violent assault on autonomy, dignity and freedom. From the perspective of this study's respondents, it is an event which is never forgotten and indeed, forms one of the cornerstones to the political identity of psychiatric survivor. In Alice Miller's (1984) analysis of our culture's child-rearing practices, she contends that it is a fundamental contradiction for parents to attempt to teach their children not to be violent by hitting or spanking them. In the same vein, survivor activists argue that involuntary treatment, which typically involves wrestling unwilling patients into restraints where their wrists and ankles are tied down and psychiatric medication is administered by injection is, by simple definition, a violent act which is traumatizing for everyone involved, staff and patient alike. They conclude that it begets the very violence it is attempting to suppress. Instead, they ask that mental health professionals and others embrace a power contract which is based on empowerment and liberating power relations. Embedded in these sorts of more egalitarian power relationships is the necessity for professionals to "inquire about, respect and address the reasons which motivate" the offending behaviours in the first place (Boudreau & Lambert, 1993, p. 83). In fact, recent research demonstrates that psychiatric inpatients who felt that staff had at least *tried* to talk to them about their inappropriate behaviour before implementing mechanical restraint were much more inclined to view their inpatient stay in a positive light (Ray, Myers & Rappaport, 1996). And, according to this study's respondents, if professionals were to ask routinely for the reasons behind their behaviours, they would discover that they are attributable to the intangible, emotional components of a power contract based on dominance -- lack of respect and dignity, abuse, neglect and abandonment --

and in its more tangible economic expressions such as poverty, poor housing and unemployment.

What are consumers and survivors going to do about it?

Certainly, it is Chamberlin's (1978) point of view that mental health professionals don't get it, haven't gotten it for over two centuries and, by extension, aren't likely to get it in the near future. Thus, it is time for consumers and survivors to take charge of their own health. However, she warns that they have a very difficult task ahead of them, one that requires energy, commitment, faith and a lot of time. Respondents of the present study felt that they were becoming weary. Paul Reeve says,

> We don't want to end up victims in a survivor role. We need to work on our own healing, move into an empowered position ourselves. We have to understand that we don't just exist to change the mental health system.

Susan Hardie agrees,

> We need to take time out to take care of ourselves so we can continue. A lot of consumers just push, push and push, trying to get some change and then they burn out and have to leave. Some never come back and they were really good people with a lot to contribute but we lost them.

Marnie Shepherd,

> Like so many things in life, you wish you knew then what you know now. There was just too much money that came too suddenly and so many of the CSDI groups were inundated with Ministry of Health paper work with no one to help them.

Adele Rosenbloom,

> I'd like there to be some sort of wonderful coming together of all these different survivors groups where there's a real respect and sharing, where people listen to each other and support each other. We need to say, "OK, let's forget the past. Let's heal the wounds and move on and create something new."
>
> M.
>
> I'm hoping we'll come together. We haven't yet. Hopefully we'll realize that for all our differences, our goals are the same and we'll begin to work together better than we have in the past. I don't think it's anybody's fault that we don't work well together. With all the problems we've had, it's a miracle that anybody's working at all.

Despite very similar goals that could have formed the basis of an ideology, many respondents feel isolated, demoralized and battle fatigued -- "victims in a survivor role." Susan Hardie says, "I think what has happened with all this participation business and the funding opportunities that went with it, is that we've actually slowed down our development -- or stopped it -- stopped what would have been a grass roots movement."

Throughout the entire research project, many respondents prefaced their remarks about mental health professionals and government bureaucrats with the statement that "I think their intentions were good.." but McKnight (1994) is skeptical. He says, "good intention is the most dangerous explanation for action there is" (p. 5). He insists that if people look beneath the rhetoric of "doing good," they will see that a justification of good intention is no guarantee whatsoever that a positive outcome will result. Certainly, from the perspective of the theoretical context of this research, the guise of "doing good" is the essential companion to a power contract based on dominance. As respondents have demonstrated, dominance can be experienced in many forms; from the overt coercion of involuntary treatment, easily recognized for what it is, to the much more subtle tactic of a suspect call to partnership based on the invisible practices of hegemonic dominance. This latter form of power contract is, by definition, much more difficult to identify and navigate. However, it has also presented consumers and survivors with opportunities for an unprecedented level of influence along with the difficulties. Relative to the "old days," consumers and survivors now have a substantial resource base which, although it has netted them their own self help and economic development organizations, has brought with it its own stresses and strains. In the face of these good news - bad news contradictions, respondents feel burnt out and frustrated, but they're also energized, committed and, in some cases, fighting mad. However, a still missing ingredient in their campaign for change is a clear ideology which is critical for the safe navigation among and between the competing claims of their fellow "stakeholders."

Disability rights

The respondents of this study have emphasized the need for a qualitative change in the power contract -- a long term, societally-based, and fundamental change that challenges all our beliefs from the micro perspective of how we raise our children to the macro concern of how we provide mental health care. One of the primary tactics for creating change, which could have been part of a fledgling ideology but one which is *not* mentioned in any significant way by respondents, is an emphasis on civil rights. Rights are protections, usually enshrined in law, which are accorded the powerless so that they are insulated against accidental or intentional abuse perpetrated within the confines of the power contract. For example, in Ontario, there are Patient Advocates stationed in every provincial psychiatric hospital to monitor the provision of psychiatric treatment and protect the rights of the patients, as defined under the Mental Health Act and other relevant legislation. Janeway, however, warns that advocacy based solely on a rights agenda may be an unsteady path to change. The problems with rights, she argues, is that they are "temporary gifts, granted if the powerful think it desirable but withdrawn at pleasure" (p. 85).

Janeway's warning aside, one of the more successful lobby groups for rights protections have been the physically disabled. Discussions of disability typically refer globally to the mentally and physically disabled (Albrecht, 1992; Gadacz, 1994) without regard to potential differences. Nevertheless, I would argue that there are substantial differences that must be taken into account. First and foremost, the idea of a mental disability usually evokes images of people who are developmentally delayed instead of those with psychiatric diagnoses. Therefore, marching under the banner of the mentally disabled is highly likely to net consumers and survivors even further misunderstandings of their public image. In addition, in speaking of both mental and physical disability, Gadacz states that "disability can never be denied" (p. 56) and, indeed, no one can dispute a developmental handicap or the reality of the loss of limbs or eyesight. Yet, almost every aspect of mental illness is contested ground. Some authors even argue that it doesn't exist (Szasz, 1974). In addition, many consumers and survivors may have intermittent episodes of mental or emotional difficulties but still function fully and healthily most of the time. Others may have had only one "breakdown," never requiring treatment again. In fact, under most circumstances, members of the general public would have no way of identifying consumers and survivors unless they are visibly marked by the side effects of present or past psychiatric medication. Also, although theories about mental illness abound, there is no conclusive agreement on what it is, what causes it or what to do about it. Consequently, as respondents have demonstrated, it's hard to develop a clear advocacy agenda that has the potential of obtaining public and political acceptance. A final and major difference between people with physical disabilities and those who might be said to have a "mental disability" is that, in the latter case, involuntary treatment is sanctioned by law. While the physically disabled may, with justification, complain of the traditionally patriarchal nature of medicine, they nevertheless retain the right to refuse treatment but mental patients can have this most basic choice suspended.

Not withstanding these sorts of blocks to subsuming consumers and survivors under the global term "disabled," many mental health professionals (as discussed in Chapter 2), have begun referring to them as "psychiatrically disabled" -- an oddly circular designation that seeks to define disability in terms of the medical specialty that diagnoses the problem in the first place. Some consumers and survivors joke that it is, in fact, a more accurate term than most people realize given their contention that mental patients have been disabled by the psychiatric treatment they receive.

As with physical disabilities, an entire professional field centred on the rehabilitation of the psychiatrically disabled has evolved. Critics of this "rehabilitation industry" (Albrecht, 1992, p. 7) argue that, in imitation of its close cousin, the medical profession, which in Marxian terms is said to "produce" disease, psychiatric rehabilitation specialists produce disability. Just as psychiatric diagnoses create spoiled identities (Goffman, 1963), a disability designation entombs people within an additional layer of a stigmatized social shell constructed of negative and marginalizing attributions. At the same time, it colonizes their identities so that they can be "worked on" by employees of both the medical profession and the more recently minted rehabilitation industry. The role of rehabilitation is to exert a powerful socialization process that first, severs people from their personal histories and then re-defines them in the language of disability and handicap -- a role which is reminiscent of the Foucauldian view of medicine and psychiatry. The skills people learn during the rehabilitation process are those appropriate to the "good patient.. docile, acquiescent, dependent on others and.. ignorant of his or her rights" (p. 48) -- an agenda which appears to be the precise opposite of the consumer and survivor vision of a power contract based on self-empowerment and liberating power relations.

When disability is viewed as a product that is manufactured through professional-client relationships, it becomes clear that it is likely to be the professionals who will have almost total control over interactions within the disability power contract (Gadacz, 1994). Physical disability groups have long recognized this imbalance and have demanded changes so that their needs are more fully recognized. While they have similar experiences and similar complaints, their agendas for change seem much more clearly defined than those of consumers and survivors. For example, they demand (not ask, not request, but *demand*) legally sanctioned equality through such vehicles as the Canadian Charter of Rights and Freedoms. They insist on full participation in the planning, monitoring and delivery of services that affect them -- and in this case it was *their* idea and not that of well intentioned professionals. They want integration into the community of their choice and Canadian society as a whole.

They also demand to be seen as individuals who must have their personally defined needs and aspirations respected and, finally, they call for systems of accountability, insisting that professionals answer both for their "actions and inactions" (Gadacz, 1994, p. 91). A final point which is considered to be absolutely central to the physical disability movement is the "dignity of risk" (p. 80). Gadacz states that the "ultimate mark of humanity (is) the right to choose for good and evil" (p. 80). In sum, physically disabled adults cannot and should not be protected against bad decisions and embarrassing mistakes.

The power of the wider disability movement has some decided appeal for consumers and survivors in that it affords them access to a powerful rights lobby group with a demonstrated track record. However, the reality is that consumers and survivors have tended to feel somewhat on the outside of these groups, unable to make their particular concerns heard. One respondent explains,

> We don't really fit in. Ultimately, society's concept of disability doesn't include people like consumer/survivors. Like, if you have no legs, you have no legs. That doesn't have to be measured. But with mental illness, they get into *how* mentally ill you are and that kind of thing. With physical disabilities, people go, "Aaawh, that's so sad." If you say you have a mental illness, people go, "Oooooh, that's scary." Like the reaction, the stigma of it is different.
>
> The other thing is, just because you have a disability, doesn't necessarily make you sensitive to other people's disabilities. I can be just as insensitive to someone with a mobility impairment as they can be to me.
>
> So this disability thing, it just doesn't fit. I write about people with "psychiatric disabilities" only so that I can use the whole human rights argument. I don't consider myself disabled -- which is not to say that people who have been labeled mentally ill don't have periods when they need a lot of support.
>
> Another problem is that the only time we interact with other disability groups is around legislative stuff -- equity, accommodation, that kind of

> thing. And, a lot of the things that the rest of the disability movement is fighting for, have been decided upon long before we even get to the table. I, myself, wrote about accommodation for psychiatric survivors in colleges and universities. I was aware that it's kind of ludicrous to be writing about accommodations for a group that has an unemployment rate of between 80 and 90%. So, we're talking apples and oranges. I stay in it to kind of keep our foot in the door -- just to keep ourselves visible so that we have a voice. But, at the same time, there's an acknowledgment that we're not even close to getting some of the recognition and access that other people with disabilities have.

None of the respondents in the present research felt that the term disabled could be accurately applied to them. Nevertheless, it carries with it entrée to some of the things that consumers and survivors value. For example, it assists them in recasting, in civil rights terms, debates over involuntary treatment or newer ideas like community committal -- a sort of psychiatric parole that every so often looms on the Ontario legislative horizon. In practical terms, the disability designation also allows consumers and survivors access to a somewhat higher rate of social assistance than offered through basic welfare However, it must also be acknowledged that, while the physically disabled don't have a choice as to whether or not they are going to wrestle with the concept of disability, most consumers and survivors have the option to choose, individually and collectively, to use or, in the end, to abandon this identity marker, judging it to be a path that may possibly offer too few rewards given the uncertainty of the destination to which it leads.

What does the future hold?

As I was ending my research interview with each of the respondents, I asked them to predict what the end of their collective story might be. Throughout the research, their descriptions of their activism had evoked many of the emotions one would associate with all sorts of life struggles. They have described themselves as optimistic, pessimistic, cynical, hopeful, weary, afraid, lonely, embattled, empowered, disgusted, and puzzled, but I note that they never used terms like bored or defeated. In concluding the results section of the research, I offer each respondent's view of the future.

> Susan Marshall,
>
> I think sometime soon, I'm going to have to move on -- to what, I'm not sure but I think I'll always be involved in some way.
>
> Jennifer Reid,
>
> I think we're going to end up divided. The grassroots activists are going to clash with the middle class activists and we're going to have so much infighting that the government is going to be able to implement any type of law it wants, and by the time we quit fighting about it -- it will be all over with.
>
> Marilyn Nearing,
>
> I'm probably going to be involved until I die because why would I give up something that gives me such joy? I am hopeful that there will be pockets of success that we can build on. People have obtained a wellness through this.... and we have a lot of dynamic leaders out there. And you know, it's really strange, but I think there might be a chance with the economy being so bad and everyone's job being threatened, there might be an opportunity for the general public, so many of whom are, right now, in a position of vulnerability to identify with us.

Paul Reeve,

If they cut the funding to our CSDI programs, people will have to search out other types of jobs just to survive and that puts a lid on things. I think there could be a future but I recognize the need for financial support to ensure that future.

Susan Hardie,

There will always be some die-hards who will remain committed. There are always people who are willing to stay in there with their hearts. They may need to take time out now and again but there will always be people pushing for change.

Marg Oswin,

The window of opportunity that we had -- the glory days -- the days of the Graham Report in the late 80s when we thought anything was possible -- that window has closed. I think we're entering a period of withdrawal from the field. We're resting, learning from our mistakes and preserving our hope for the future. It's still there. Everytime we get together in a group, I feel a bond, a unity, an enthusiasm that's always there. That's not gone anywhere. We're just hibernating right now, but we're still alive. I think another opportunity will come and we'll be better able to deal with it. It would be nice if it happened in my life time. I don't know if it will ... but as long as people are oppressed, they'll rise up and fight it.

Donna,

I think we're drifting apart. Consumers and consumer groups are isolated from one another. The funding has never been adequate. There are a lot of movements that grow without funding but I don't think this is going to be one of them. And we all have different agendas for change. I would like to say that I see this as a challenge but I don't. I see it as the thing that will cause this particular movement to fizzle out. We had our chance and we missed it.

A respondent who preferred anonymity,

You can't erase people. You can put them down in one place but they pop up somewhere else. If you go look at the archives at Queen Street, you'll see that survivors at the turn of the century were writing letters and asking the same questions. "Hey, I worked in the laundry for 15 years, how come

I never got paid?" Letters from the *turn of the century* saying the same thing that we're saying now. You can't silence people because it always comes up in some other, more subversive way. I tend to look at things in a really broad time line. Like, I'm not really thinking about the next five or ten years. I don't have a vision of the end.. what it's going to look like. I also tend not to worry about the unity of the movement because I don't necessarily feel that unity is a good thing. I think people's individual voices get drowned out. So, I'm the kind of person that shrugs and waits to see what will happen. I do my best in my corner of the world and if I have an opportunity to affect some change, I do it.

Sue Goodwin,

Well, our future is going to be different than the past. I don't know if it's going to be better. I hear voices out there in places that I wouldn't expect to hear them and what we have to say isn't such a cry in the wilderness as it used to be. We're out there. We're trading information on things that are happening in Toronto, the States and even the Yukon. And we're all saying the same thing, just in different words. The little dribble of funding we got from the government helped our movement to form but it's not going to keep us surviving. We have to find our own funding. We're not going away.

Walter Osoka,

I need to get a job. I'm on unemployment right now. But I'd like to take part as a board member or a volunteer, whatever, as long as I can.

Dave Stewart,

Psychiatry is not an easy thing to take power from and as liberal as certain professionals sound, they have a lot to protect and they will protect it. But I don't think you can quite get us to go away. Look at the women's movement and all the trouble they've had. You can't stop these things once they've established some history, you can't stop them completely. And we have our own bit of history now.

Hugh Tapping,

We can't be defeated as long as the system is as nasty as it is. It will keep manufacturing new versions of survivors.

John (a pseudonym)

I think we've come a long way. Our organizations have proved a lot. Ten or fifteen years ago, the movement, if there was a movement, didn't have any real resources. I think things will get better unless the Ministry relaxes things and ignores its own guidelines for consumer participation on Boards and committees.

Patrick Brown,

I don't want to do this for the rest of my life. Chances are that in the next five or six years, I'll be moving on. My ultimate goal is to go overseas and do community development work.

M.

It would be interesting if I could just fly off somewhere and come back in ten years and see what's happening. It's very fragmented right now. There are all these rivalries and jealousies. It's all tied up with power and money.

Marnie Shepherd,

All movements go through these things. We have got to spend time thinking about what's going right with our organizations so that we don't become caught up in everything that's going wrong. I can go visit our CSDI groups and they have things going horrifically wrong with them at the board and staff levels, but I sit down to coffee with a member coming in the door -- which is why the group exists in the first place -- and he just thinks everything is hunky dory. It's not as bad as we think it is. There might be organizational trouble but the people that want to use the organization -- the members -- what they need is still there.

Adele Rosenbloom,

I really hope that survivors can come together and create a movement that *will* enable real change to take place. I hope we can learn to support each other and give each other the kind of respect we need so that we can work together. I see it happening in small ways.

> Jennifer Chambers,
>
> My hope is that the movement will develop an independent vision of what consumer/survivors want to have happen so that mental health reform doesn't end up being an endless series of tiny variations of what we have now... so that there will be some actual, real, life-changing alternatives developed so that we can see that it doesn't have to be the way it is now. People need to start thinking from the bottom up... which will probably never happen within the Ministry of Health. People have to be willing to give up the false protection of psychiatry if they want to move forward.
>
> Jane Pritchard,
>
> I'm very good at old sayings and one of them is "right is might." We're not going to go away quietly. In fact, we are not going to go away *at all.* This is our fight! This isn't about their jobs! This is about dignity and respect and the right to a life. So, you know me, boy, don't fuck with me when I believe I am right. I'm not going away and there are a lot more just like me.

As a participant in the present period in mental health history myself, I have occupied a front row seat for the political, bureaucratic and professional drama in which the consumer and survivor movement has played its role. At the time of writing (January, 1997), mental health reform planning continues, seemingly unabated, fully nine years after the publication of the Graham Report. Thus, in this respect, I would say that not much has changed. However, the radical neo-conservative agenda of the present government has meant that the political winds in the province have shifted dramatically, and frighteningly, for all health care providers. While the Conservative government has promised that the 17.4 billion dollars in health spending inherited from the New Democrats will remain at exactly the same level throughout their tenure, within this funding envelope, wide-ranging changes are planned. Presently, a government appointed Health Services Restructuring Commission is sweeping across the province, recommending hospital closures and, in one case so far, the closing of a provincial psychiatric hospital -- in Thunder Bay, not far from Susan Marshall's home town, Fort Francis. In Toronto, the Clarke Institute of Psychiatry, a small specialty hospital which has traditionally focused its energies on research, is planning a merger with Queen Street Mental Health Centre amid howls of protest from the unions involved. Community mental health programs have been cut by 2% and another 3% is pending in what has been termed an administrative efficiency exercise.

However, the Consumer/Survivor Development Initiative's budget remains intact and, while it could be argued that it has but a slim toe-hold in the overall mental health funding arena, a recent evaluation of the program demonstrated that its many self help and economic development projects have contributed to a reduction in the length and frequency of stays in hospital for their members and, further, doctor visits and crisis contacts were down (Trainor et al as cited in Wilson, 1996). Thus, these projects have reinforced Chamberlin's (1978) original thesis -- self help works and its cheap -- making CSDI the epitome of the cost-effective vision that the Conservative government holds for the entire health system.

Individually, however, many consumers and survivors have been hard hit by cuts to welfare and the allowances paid to single mothers. Presently, disability benefits remain unchanged but a pending alteration in the criteria for obtaining disabled status has many recipients worried. In addition, proposed changes in rent control legislation and a recent shift to local municipalities of the responsibility for subsidized housing may mean that further hardships are forthcoming.

Nevertheless, it is my impression that, while the political climate has produced chaos in the formal mental health service sector, frightening professionals and now, bureaucrats, even more than was the case when reform was originally proposed, paradoxically, it has also created a peaceful moment for consumers and survivors. The intense pressure of "partnership" seems to have abated. The faint, but rallying scent of betrayal, once again, is in the air. In the wake of the closure of the Advocacy Commission, prominent survivor leader Pat Capponi, seems to have regained her angry edge. She writes,

> Since 1978 I have painstakingly remade myself into someone I could live with, someone I could respect. By standing up for others, I learned how to stand up for myself. As hard as it was living on welfare in a psychiatric boarding house, I stayed alive when others failed -- by learning to believe in possibilities and in people.
>
> I assumed that all we needed to do was expose conditions and government would be forced to act.
>
> I kept that belief, and it kept me, for over 17 years, years of meetings with ministers of health, bureaucrats by the handful, and mental health professionals. It was often brutal, frustrating, every psychiatric survivor's death a failure I wore personally. I hadn't done enough to let people know. But I believed, you see, and my community believed in me. (NOW Magazine, Feb 22-28, 1996, p. 17)

In addition, while it remains true that consumers and survivors continue to be recruited for never-ending planning exercises, and they still conduct themselves rudely at public forums, yelling as loudly as ever at embarrassed but ever-polite professionals and bureaucrats, their participation in most aspects of the mental health system is much less of a disturbing novelty. Habituation carries with it its own threat. Repetition tends to de-fang once sharply confrontative critiques and a ubiquitous presence can become a recipe for a new form of invisibility, one born of familiarity. Nevertheless, I believe that, in the short term, consumers and survivor might benefit from a period of relative calm so that they can work on getting their own house in order. In the long term, I tend to agree with respondents' more optimistic views of their future: They now have their own bit of history and they're not going away.

In conclusion

In keeping with the theoretical context of the research, the embryonic ideology of the consumer and survivor movement, at least as it is defined by this study's respondents, centres on power and its uses and abuses in our society. Consumers and psychiatric survivors appear to have fastened on a fundamental set of questions which challenge the foundation of all social relations. Dominance is the basis for most of our present power contracts, from small, local and intensely personal familial relationships to large, worldly social relations that characterize operations in government, politics and the mental health system. Power contracts based on self empowerment and liberating power relations are currently reasonably rare exceptions to the dominant rule and, given the general invisibility of power that is so much a part of a society founded on principles of hegemonic control, such a fundamental alteration in how we relate to one another remains extremely difficult to institute in the first place and to maintain in the second. Certainly, when consumers and survivors began developing their own organizations, they merely reproduced the damaging power relations they so much feared. But, as Jennifer Chambers so succinctly puts it, "People who've been fucked over, are fucked up." When aspirations and visions for the future are painted with the aid of a large philosophical brush, a natural frustration is to search vainly for what, specifically and concretely, consumers and survivors want. Simply, but broadly stated, they seem to want a life. However, the necessary and time-consuming precursor to that life is defining their beliefs and values which then will constitute the rock-hard foundation upon which a more refined advocacy agenda can rest. It is a painful and lengthy process that may take decades to complete. In the current neo-conservative political atmosphere where so much energy is focused on administrative and managerial changes in the formal mental health service sector, consumers and survivor may have attained a moment of peace where they can tackle this complex task. As Marg Oswin says, they are hibernating right now, waiting for another window of opportunity when they will be better prepared. The challenge will be to develop an ideology which is clearly differentiated from both the government's need to control costs and what respondents view as the professional protectionist agenda. It is a vital challenge.

CHAPTER 11

FINAL THOUGHTS AND UNDERSTANDINGS

This study began with a description of life in a psychiatric hospital where the underlying tenets of the power contract (Janeway, 1980) between staff and patients appeared to be straightforward. The patients needed help and we, as professionals, were trained to be helpful. However, each group had a different perception of first, what was wrong and second, what to do about it. In the midst of a tense and chaotic ward atmosphere, coupled with community discharge destinations that included poverty and violence, both staff and patients alike seemed to conclude that nothing changes and no one gets better. However, staff-patient relationships were not the only interactions in the hospital based on power. Staff, who occupied a position of power in patients' lives, felt themselves to be powerless in the face of administration, often raising many of the same sorts of complaints that the patients had of them. "Our concerns don't matter. We have no say in the decisions that affect our lives." And administration, in their turn, appeared to feel powerless in relation to the Ministry of Health, seeing its representatives as capricious, sometimes punitive and oblivious to the realities they faced.

A review of the history of insanity pointed out that staff and patients of the very same hospital had been having similar experiences for nearly two centuries. Although periods of reform have come and gone, along with a variety of treatment modalities which alternately emphasized nature or nurture etiological theories (Rogers & Pilgrim, 1993), conditions for mental patients have remained pretty much the same. They live outside of society's universe of obligation (Gamson, 1995), exploited and marginalized, feared and fearful, yet consistently asking for the basic human necessities; friends, family, a home and a job.

Turning to theories of social power, I argue that our social structures are based on power relationships characterized by dominance. Alice Miller (1981, 1983,1984) views our Western child-rearing practices as inherently harmful, mainly because they are disrespectful of children's developing and fragile emotional lives. From her perspective, overt abuse is merely an extreme example of a general social tendency to sanction or ignore violence against children. As a result, ours is a society that can quite readily produce adults whose most salient, though unconscious view of themselves is as victimized and powerless. Through a process of "splitting off and projection" (Miller, 1984), which means that adults can unknowingly partition off their painful memories of childhood powerlessness and project their fears onto their own children or, in the larger social context, people who are vulnerable and marginalized, society becomes understood as a place where it is "natural" for some citizens to have a lot while many have a little. Under these circumstances, one portion of the population may be denied the opportunity to fulfill its needs, which at their most basic, relate to access to decent housing and freedom from poverty and hunger -- needs which are presently being called broader health determinants (Evans, Barer & Marmor, 1994). When society becomes divided into those who are inside the universe of obligation (Gamson, 1995) and those who are outside, it creates a duality of thinking that severs and polarizes; powerful and powerless, have and have not, harm or be harmed. In addition, Gil (1996) views denial of opportunity as a form of initiating social violence which he defines as a set of actions that constitute the beginning of a three-part spiral of violence. The second part of this spiral is the threat of reactive counter-violence created when powerless people are unable to meet their own needs, no matter how hard they try. In such an atmosphere, the tendency is for society to both produce and submit to an intricate web of rules and regulations, thereby creating the third part of the spiral, a repressive social response which is, itself, a form of violence. In the production of his three part theory, Gil is employing a broadened definition of violence which, in Wartenberg's (1990) terms, relates to all activity, visible and invisible, which produces and maintains dominance. From Janeway's (1980) perspective, these are the sorts of forces that result in the creation of a power contract based on dominance where those in power seek control over the less powerful, by force if necessary, employing an "it's for your own good" justification designed to elicit both compliance and gratitude, creating an invisible web of hegemonic control whereby both the powerful and the powerless repress their uneasiness and agree that "it's just the way things are."

In the case of mental health and psychiatry, the close confines of the psychiatric ward, the emotional crucible of the family and the mean city streets are examples of initiating social violence that can give way to reactive counter-violence. While incidents of actual violence among mental patients are, in fact, low (Arboleda-Florez, Holley & Crisanti, 1996; Monahan & Arnold, 1996) they, nevertheless, are accorded a saliency which drives legislation. The power of psychiatric science is backed by a set of laws that sanctions coercion, creating a pathway for institutionalized violent responses in the form of involuntary commitment and forced treatment. The invisible power of hegemony also allows citizens, who would otherwise view themselves as decent people, to ignore widespread and well-documented abuse and violence perpetrated against mental patients at the hands of the community and state (Roeher Institute, 1995) while, paradoxically, producing a government policy which refers to this same group as "survivors" (Putting People First, 1993). The interactive spiral of initiating social violence which denies mental patients the fulfillment of even their most basic human needs (friends, family, a home and a job), followed by a small but salient show of reactive counter-violence which, in its turn, releases the meta forces of legislated violence (Gil, 1996), creates and re-enforces a mental health system which could be said to be structurally violent. In sum, a place where there is the strong potential that nothing will change because no one *can* get better. And so it has been for nearly two centuries.

Power contracts based on concepts of empowerment and liberation appear to be rare in practice but, nonetheless, populate our utopian dreams of the future as evidenced by their regular emphasis in the rhetoric of mental health reform. Presently, we are in the midst of another period of reform where, in line with wider trends, the government of Ontario has de-emphasized the role of its traditional partners, psychiatrists and other mental health professionals, and instead, recruited consumers and psychiatric survivors to help with the production of its mental health policies and plans.

While the government's logic is likely based on certain pressing problems such as an increasing cynicism regarding its own role, a lessening of faith in the infallibility of health care professionals and an ever-increasing set of snarled and diverse interests that demand satisfaction (Boudreau, 1990), its move to anoint consumers and survivors with partnership status opens a door which this study's respondents vow will not be closed. In their turn, consumers and survivors, have had a noticeable impact on mental health planning, although individual respondents tended to see themselves as ineffective. As this unique moment in history unfolds, the contribution of this research is the view that it offers from the other, forgotten side of the power contract -- marginalized ex-mental patients whose opinions have historically been almost completely ignored.

Gil (1996) argues that non-violent liberation movements which, in Janeway's terms, come together to share a mutual sense of mistrust in the actions of the powerful and form organizations which mobilize effective political action are, in the long term, a powerful social force that promises to erode the foundation of our structurally violent society. The purpose of this research was to describe a nascent example of such a movement which, while admittedly fragile, continues to struggle.

A review of the research findings

The initial research question asked, by what process have ex-mental patients become political activists? In response, respondents told stories that took the archetypal form of an odyssey. After sometimes years of suffering, they reluctantly asked for help, feeling that they had personally failed but, nevertheless, fully prepared to acknowledge that the experts must know something they didn't. They thought a cry for help (even when offered in a disguised form) would elicit empathy, caring, encouragement and guidance. Instead, many encountered the violence of involuntary commitment, forced medication and electro-convulsive therapy, standard psychiatric treatments which respondents call abuse and which they say only served to make their problems worse. In the best of circumstances, they report that they simply got nothing -- no answers and no help. These experiences transformed them into sadder but wiser people who now know what is *really* going on. They think of themselves as lucky to have been able to "manipulate" their way out of the trap they felt they had innocently entered and, although many respondents eventually received help from a specific psychiatrist or other mental health professional, they interpreted this fact to be merely the exception that proved the rule. In their view, their experiences amounted to a metaphoric journey which created a special bond among their fellow travelers based on a unique form of oppression related to what they think of as the mental health system's attempt to capture and destroy their minds and spirits.

In reclaiming and re-creating their own identities, respondents relied heavily on the mirror of the Other which, in this case, is composed of mental health professionals. These experts, from which they had originally expected empathy and guidance, provided the road map which showed respondents all they should *not* be; fearful of their own emotions, dedicated to the appearance rather than the reality of ethical conduct, contemptuous of the very help they are supposed to be offering, self-interested, and above all, embedded in a web of rigid rules and regulations which, in the case of the Cedar Glen tragedy, left them focused on legal rather than moral imperatives. However, upon deeper reflection, respondents concluded that perhaps mental health professionals were more like consumers and survivors than they had at first thought. "Everybody's afraid," says Jennifer Chambers. Consumers and survivors are afraid of losing what little they have. Professionals are afraid of losing their jobs. Respondents observed that the phrase, "I'm not in control, there's no money, no support," has become the universal complaint whether one is a consumer, survivor or a mental health professional.

Respondents were equally candid about their views of their own efforts to form economic development and self help organizations with funds from the government-sponsored Consumer/Survivor Development Initiative. The sudden influx of large sums of money set freshly hired consumer and survivor staff against the impoverished volunteers that made up the bulk of the membership of the newly formed organizations, creating a have/have not scenario that fostered dissension and rancor. Respondents used the colorful term, cannibalism, to describe the spate of in-fighting and back-biting that sapped their energy and opened fresh wounds. They concluded that it's all about power. Having, themselves, been terribly hurt by what they view as the misuse of power, they recoiled at its expression within their own ranks. "We need someone to strike out at and it's easier to strike out at one of our own." Indeed, their flagship organization, the Ontario Psychiatric Survivors Alliance (OPSA) folded under just these sorts of pressures, leaving respondents feeling shocked, embarrassed and saddened. While this very public downfall is a living example of what disability groups see as a fundamental human right -- the "dignity of risk" (Gadacz, 1994, p. 91) -- it nevertheless serves as a reminder that failure, while almost always instructive, is also painful. Hugh Tapping says, "It's the most cruel thing there is to raise people's hopes and expectations and then just not deliver, and we did that."

On the subject of their new-found partnership status with government, respondents expressed themselves to be both flattered and puzzled, but above all, suspicious. "It wasn't *our* idea," they said. By this assertion, they did not mean that they didn't wish for, and in many instances, demand change. They simply had not foreseen the idea of partnership as the solution to their complaints. Instead, "old time" activists had tended to endorse self help as the path to individual change, which would lead, eventually, to wider systemic reform. Nevertheless, they recognized the opportunities inherent in their new-found popularity, but also felt drained by the constant effort to get professionals to listen, the apparent lack of visible change and the disturbing feeling that they had been, in fact, used; pitted against psychiatrists and unionized labour in service of the government's down-sizing and reallocation agenda. In addition, they noticed that the idea of partnership only extended to the point where issues of autonomy and freedom were raised. "Professionals believe in partnership as long as they can maintain control." They concluded that mental health reform, in its present incarnation, could not possibly work because "the power dynamics haven't changed."

In the midst of the pressures from the influx of funds and the government's call for partnership, consumers and survivors failed to distinguish their own advocacy goals as distinct and separate from the many other interests represented in the mental health reform process. In the final results chapter, they tentatively map out their movement's ideology. While a civil rights agenda may hold some promise, respondents actually concentrated more on the need for what they called emotional and economic supports. To them, emotional support means an emphasis on empathy, guidance and encouragement instead of involuntary commitment, forced medication and electro-convulsive therapy. It also means friends, family and a community. Economic support is defined as a home and a job. Some respondents were optimistic that they would, eventually, be able to achieve their political goals. Others felt that their fragile movement was already drifting apart, having missed an important window of opportunity that was now closed. However, most agreed that "you can't erase people." They point out that, although they've been saying the same things for over two centuries, there have always been people who have been "willing to stay in there with their hearts."

So, what's it all about?

While it is conventional to end research reports with a discussion of what implications the present project might have for the development of government policy, I find myself unwilling to proceed along this traditional but narrow pathway. The utility of qualitative research lies in its ability to range beyond the limited confines of tradition and speak to a wider audience. As a result, readers are the final arbiters of its usefulness and, while affecting the evolution of government policy may be one of the eventual results of a project such as this, it is by no means the only, nor even the most likely outcome. In addition, the purpose of qualitative research is more to raise questions and stimulate thought than it is to provide answers. Consequently, I cannot offer even the illusion that I have arrived at a polished set of conclusions. It is also entirely possible that I have been led to a collection of understandings which may differ substantially from those that readers, themselves, will develop. This potential diversity of impression and opinion is a hallmark of what I would call the rather satisfying ambiguity of qualitative methods in that the research product remains interactive long after the last interview is concluded and the final line of manuscript typed. So, too, will my own thinking evolve but, at this time and in this place, the thoughts that follow are my personal take on what it's all about.

A legacy of violence

First, I think it is important to revisit the reality that the story of the mental health system, historically and in its present incarnation, is nothing if not a tale of violence and tragedy. Consumers, survivors, families and professionals see, hear, and experience acts of incredible violence no matter what their "paradigm" or group allegiance may be. The viewpoint that mental illness is exclusively a biological disorder does not protect proponents against witnessing unbearable anguish as people are tormented by the vicious demons of schizophrenia or weighed down by the "black dog" of depression that sentences them to a despair so acute that a vocabulary is yet to be developed that can adequately describe the pain. Family members weep in agony as they stand by, wanting to help but unable to reach through the veil of "disease" that separates them from the seemingly lost soul that once was their precious child, wife, mother, brother, sister or father. On the other hand, a social causality paradigm means listening as people recount incidents of child rape and torture perpetrated within the confines of what our society anoints as our most precious resource, the family. In this instance, families must choose between retreating into angry and isolating denial or being torn apart by the revelations. Whichever course they take cannot insulate them against their worst fear; that sometime in the near future they may be bowed down by the grief of suicide when their loved one can no longer go on, or, perhaps equally as horrific, forced to watch helplessly as their son or daughter takes to the streets, disoriented, vulnerable and repeatedly the target of physical and sexual assault. If, as patients or ex-patients, people have experienced these things first hand, they may muster a tentative cry for help, but they contend that it is met with more of the same violence as they are forced into institutions where assaults are common and then discharged to housing which is violent and ghettoized. And it is the clearest reality for people who call themselves survivors that many, many of their peers have not, in fact, survived.

I repeat these realities here because conducting this study has taught me how easy it is for me to allow them to slip away. Even as I wrote the above passage, I had to remind myself that I was not recounting the violent incidents that have accumulated over a century, a decade or even a year. I was simply talking about the things I dealt with *last month* in my work as a psychotherapist. While Gil's (1996) theories call for a broadened definition of violence so that it can include neglect, abandonment and a denial of opportunity, the violence that is often the common currency of direct service in, or experience of, the mental health system is of the narrowly defined, commonly understood kind -- physical, sexual and emotional abuse. As a society, we seem to be collectively amnesic for the violence we both create and endure. In the mental health system, our endorsement of involuntary commitment and forced treatment colours all that we do. Study respondents insist that it is these coercive and violent aspects of psychiatric treatment that *create* survivors, not because all people who identify as survivors have experienced them, although many have, but simply because they exist. While, for good and substantial reason, respondents are unable to see beyond their own experiences of forced treatment and tend only to view psychiatrists who wield these powers as, at best, untrustworthy and, at worst, sadistic, I know from my own point of view that whenever force enters what was supposed to be a helping relationship, everyone is diminished; the community worker or family member who called the police, the psychiatrist who wrote the order, the nurses who tied the patient down in restraints and the other patients and staff who witnessed the event. Susan Hardie asks, "Is this health care?" This is an absolutely central question. As a mental health professional myself, nothing in my training taught me that force and coercion is helpful, yet I work in a system governed by laws that sanction such measures in the alleged service of the protection of wider society. As consumers and survivors continue to make their presence felt, whether as partners or in the less friendly role of political activists, the question of involuntary commitment requires centre stage in future discussions because it is the foundation upon which the architecture of the present mental health system rests. In Hegelian terms, it is the coercive threat that maintains a power contract based on relationships of dominance and subjugation, relationships which in contemporary language are called oppression. The reality is that an "unjust order negatively affects the oppressor as much, if not more than, the oppressed" (Memmi as cited in Duerr, 1996). While the entanglement of caring and control is an historical fact of the mental health system, must it also be its future?

The power of powerless people

The point of Janeway's work is to point out that powerless people are not, in fact, totally powerless. In the case of this research, consumers and survivors have demonstrated themselves to have had a powerful effect on mental health reform planning.

Telling stories is powerful. Respondents regularly testify at public forums and legislative hearings using well-told, intensely personal and highly emotional stories. Their presentations are all the more powerful if, as consumers and survivors contend, they live in a society that fears the open expression of emotion.

Sheer numbers are powerful. The presence of hundreds of consumers and survivors in the formerly private domains of mental health professionals and Ministry of Health bureaucrats is a powerful signal that change is underway. Their views and their language have begun to seep into formal and informal mental health parlance and their advocacy efforts have shifted the tone and the tenor of reform plans.

Standing up and yelling is powerful. When they have the opportunity, which is admittedly less often under the present Conservative government, consumers and survivors continue to publicly berate professionals and bureaucrats who have yet to yell back. While this sort of confrontative style may lose its shock value over time, so far it seems to be serving its purpose -- consumers and survivors are having their say, *fortissimo*.

However, these sorts of victories, important though they may be, are largely symbolic and respondents have declined to celebrate them, viewing planning for change, as compared to actually making change, as two different things. Historical evidence supports them in this view. While the mental health system has repeatedly attempted its own reform, positive outcomes have been sporadic and short-lived, rapidly deteriorating into the same degradation and violence they were supposed to alleviate. In addition, consumers and survivors seem less concerned with management and administrative issues which are the focus of most of these planning exercises and instead, appear more interested in the quality and nature of what, for them, is the system's most salient power contract, the professional-patient/client relationship. It is here, in this intimate and private space, where help in the desired form of empowerment and liberation does, or does not, occur. In the vernacular, its where the rubber hits the road and so far, there has been little discussion about actual change in this albeit micro, but highly critical, power contract. Finally, consumers and survivors exhibit an urgency that is not shared by professionals and bureaucrats. While one respondent acknowledges that reform is likely to be a long, long process spanning much more than just five or ten years, others say, "Unless you *do* something (soon)... I'll be dead" (Church, 1996, p. 33). Indeed, reform *should* mean actual change, but nine years into the process, not much has really happened.

Presently, however, the Conservative government seems poised to order a massive restructuring of the entire health care system but the juxtaposition of almost a decade of inertia against sudden, overwhelming change is much more a source of anxiety than comfort. If customer satisfaction is to stand as a credible logic for the many changes that are about to be visited upon the Ontario mental health system, then consumers and survivors must retain their high profile presence during and after implementation phases so that they can assess actual outcomes. When all is said and done, it is here, in the practical expression of mental health reform, where the success -- or the failure -- of their advocacy efforts will finally be revealed.

As a final note, it is important to recall that advocacy is, by definition, the art of persuading powerful others to change. Self help, conversely, focuses primarily on interpersonal growth, with social change emerging as an important but only secondary goal. Strong self help groups provide a protective shelter for the generation of self esteem, confidence and pride. They also spawn committed advocates who can do battle effectively in the more dangerous political arena, but only because they are imbued with the sure and certain knowledge that they have the support of their peers and the comfort of a welcoming home-base to which they can return. Chamberlin (1978, 1990) is adamant that the establishment of a powerful self help network is essential to consumers' and survivors' well-being, both individually and collectively. I agree. Certainly, one of the great regrets expressed by this study's respondents is that consumers and survivors don't "stick together." Indeed, effective advocacy depends on solidarity. But solidarity can only arise out of repeated opportunities to spend time in the company of one's peers, and in circumstances that assure freedom from outside influence. The government's creation of the Consumer/Survivor Development Initiative (CSDI) may be the harbinger of a thriving self help network. However, as respondents point out, government funds come with "strings attached." In order for self help to succeed unequivocally, I believe that there must be a clear, emphatic and independent commitment to its ethos -- one which arises solely from within the ranks of consumers and survivors, themselves. The results of this research suggest that the government's clarion call to partnership has, in effect, diverted activists away from the premiere task of building a solid foundation for their movement. Now may be the time to return to this basic task.

The powerlessness of powerful people

Janeway's concept of power contract is designed to point out the power of powerless people. It does not, however, account for the powerlessness of powerful people – the thousands of mental health professionals who appear to be the primary target of respondents' ire. While on occasion I have been similarly critical of my own and others' professional roles in the mental health system, I nonetheless found myself moved to sympathy for my beleaguered colleagues.

There is unquestionable substance to the criticism respondents level at workers in the mental health system. However, I noted that consumers and survivors recognized their own sense of fear and powerlessness reflected in the demeanor of the mental health professionals from whom they had received service in the past or with whom, in the present atmosphere of partnership, they share membership on boards, committees and planning groups. Mental health professionals, respondents say, are just as afraid as we are. Certainly, this view is consistent with my own experience where I observed that power relationships based on dominance are the norm in the rigidly hierarchical, top-down organizational structures in which most professionals work. Workers who, themselves, feel frightened, disregarded and disempowered are predictably vulnerable to reproducing these same conditions among their own patients and clients. In addition, professionals are constrained by the formal and informal rules and regulations that are the price of membership in the inner circle of power. They eschew bad manners and, instead, swallow their anger (Church, 1996). While they have tried to insist that consumers and survivors might benefit from being "nice," (Melville Whyte, 1996, p. 22), consumers and survivors, in their turn, aren't buying it. Anger, they say, is a natural and healthy response to oppression and its expression is liberating. This is valuable advice for mental health professionals who are, themselves, suffering their own form of oppression.

In fact, as long as professionals work in a system that supports dominance, their ability to be helpful in the way that consumers and survivors are demanding is extremely limited. Powerless people simply cannot empower and liberate. One of the clearest findings of the present research is that respondents do not agree with Thomas Szasz (1974) when he asserts that mental illness is a myth. Instead, they describe deep suffering and a desperate longing for help. Mental health professionals want to help. However, professionals who, themselves, lack the emotional support of empathy, guidance and encouragement are predictably unable to offer these same comforts to their patients and clients. In short, while the majority of mental health professionals remain frightened and disempowered, it is possible that nothing *will* change because no one *can* get better – surely the most costly and ineffective strategy of all.

Power as liberation

Perhaps the most important finding of this research lies in the briefly mentioned, and thus easily missed fact, that many respondents reported that they actually found help within the confines of the formal mental health system, and it was provided by a mental health professional. However, respondents moved swiftly over this revelation pursuing, in preference, impassioned discussions of where and how the system failed them. Given their political role, it is understandable that their focus is on what's wrong, rather than on what's right. Nevertheless, I am tantalized. The theoretical stance of this work proposes that help is best provided when the professional - client/patient relationship is built upon a paradigm of power as liberation rather than power as dominance. However, the helpers, of whom respondents speak so favourably, exit quickly from the narrative stage, leaving the impression that receiving help from a mental health professional is nothing but a lucky accident. And perhaps, within the broader terrain of the mental health system, this view is accurate. However, I can't help but want to know more. What can be learned from these instances? Within the confines of the present work, it can only be documented that they occur. Although this is, regrettably, only a faint beacon, it's importance should not be minimized. Prevailing wisdom, often propounded both at a professional and at a lay level, identifies a diagnosis of mental illness as a life-long burden, sentencing sufferers to the bleakest of futures characterized only by decline. The respondents in this study each received such a sentence, yet they stand as living proof that things *do* change and people *can* get better. From the perspective of this work, exactly by what process this miracle occurs, unfortunately, remains a mystery.

A political identity in search of a future

The final understanding that I take from my research experience surrounds both the opportunities and the limitations of "psychiatric survivor" as a political identity. All study respondents rejected the professionally-generated term, consumer, preferring instead the more militant identity of survivor. Indeed, the term psychiatric survivor figures prominently in Ontario mental health policy, for reasons which are perhaps the government's own but, nonetheless, its presence formally acknowledges a group of people who believe that psychiatric treatment, as it is currently constituted, is the punishing instrument through which survivors are created. The utility of the survivor identity is as a political tool. It valorizes the suffering that people have endured and connects it to a specific cause. It politicizes individual experience by illuminating the oppressive social structures that create stigma, marginalization, violence and poverty -- experiences which, indeed, can only be survived. However, to be a survivor, even a publicly acknowledged one, is to embrace an identity without an obvious future, despite its strong past. The word means, in its standard definition, to have made it through, to have outlasted the threat. But then what? There is no vision that extends beyond this horizon.

In addition, having escaped once is often thought, erroneously, to provide added confidence in that survivors now supposedly know that they could make it through again, should they once more be tested. However, as study respondents have pointed out, ignorance provides its own protection. In fact, "knowing" can become a formidable enemy because its legacy is fear. Indeed, one of the greatest concerns for respondents is the fear of retaliation. Could they survive a second time? I didn't sense that respondents believed that they could. As a result, the survivor identity may offer only the appearance of power and, like whistling in the dark, protect only so long as the "enemy" believes in its strength.

Further, one respondent states, "I want to do more than just survive." While no one can deny the initial experience of liberation that the adoption of the survivor identity seems to provide, there is nevertheless the possibility that, without careful reflection and management, it may become claustrophobic over time, especially in its less maneuverable collective expression. The present and pressing challenge for the consumer and psychiatric survivor movement is to develop a shared ideology that clearly describes their advocacy agenda. While it is true that their movement is in its infancy and may struggle with this task for many years to come, a logical but perhaps unrecognized first step along the developmental voyage may well be a strategy for exiting from the conceptual confines of their own survivor identity. "It's hard for people to even imagine something different," says Jennifer Chambers and in this, she may be correct. The future for consumers and survivors seems to rest in a place where presently it cannot be imagined and their difficult task is to reach beyond "just surviving" towards a clarity of vision and purpose that will guide and sustain their movement. To fail to do so will only leave them rudderless and vulnerable, the regressive and all too familiar state from which many movement members have only just emerged.

Strengths and limitations

The greatest strength of the present research is also its main limitation. The fact that I am an integral actor in the events that I study provides me with a view that others who are more remote cannot have. However, such proximity may very well limit my understanding in ways that I try, but fail to mitigate. One help has been time. The study has taken four years from beginning to end and, although I have often wished that I could have suspended my other duties in favour of a concentrated research effort, in the final analysis, I have found that time has been on my side. For example, it has allowed me to reflect between respondent interviews because they were often months apart. It also assisted in the writing of the final research report because I have been able to deepen my understanding of the data in a layered fashion, moving from description to analysis in a slow, step-by-step process which allowed space for reflection and correction. Somehow, a much-favoured position is not so myopically or fervently held when it has been resting dormant for weeks on end as other life events take over. Finally, I have had the benefit of objective feedback from my own dissertation committee members as well as a number of friends and colleagues, each of whom has gently but firmly insisted upon the re-examination of my more stubborn blind spots. Criticism, and I use the word in its artistic sense, has catalytic properties which not only improve the end product, but urge it towards becoming something it could never have been were it left alone to fulfill but a singular vision. As a consequence, this project is a collaborative effort with many people having given their time and energy. For these gifts, I am grateful.

Implications for future research

The study of ex-mental patients in their new roles as consumers and survivors has only begun (Everett, 1994; Church, 1993; 1996, Duerr, 1996) and research which concentrates on them as functioning, contributing members of society is confined to the present work. In short, the field is in an embryonic stage, awaiting further discovery and definition. This research, however, points to some potentially fruitful avenues for inquiry. For example, power and power relationships in mental health are only now emerging as important constructs for inclusion in research which is aimed at developing an understanding of the mental health system as a whole, and consumer and survivor participation in particular (see the Canadian Journal of Community Mental Health, Fall, 1996). However, the utility of a power analysis was not lost on this study's respondents and, in fact, they contend that "it's *all* about power." While this statement may represent too firm a conclusion, nevertheless, there is no doubt that the application of theories of power promises fresh understandings, as this research demonstrates.

The perception on the part of respondents that there may well be a gap between reform intentions and eventual implementation realities points to the need for extensive research related to mental health reform itself. While 2.8 million dollars has recently been awarded for exactly this sort of activity (Goering, Private communication, 1997), there is an intense interest in understanding what, if anything, will change. And if it can be demonstrated that change did occur, then it must be determined whether or not it was positive, negative or simply a rearrangement of old patterns. Consumers and survivors might also want to ensure that they have a place in these sorts of research activities given the fact that they contend that it is *they* who will be the best judges of whether or not the mental health system has, or has not, reformed. In this vein, there is also a role in research for consumers and survivors in the production of their own knowledge. As the movement expands its talent pool, qualified researchers who also identify as consumers or survivors are likely to swell in number and their contribution to the traditional ways of knowing will take us into new territory.

There is also a need to develop an understanding of the impact of consumer and survivor participation. While this study's respondents feel that they haven't achieved much at all, there is evidence that they have had a substantial effect. Such questions as what is the nature, direction and consequence of this effect represent tempting new directions for research activity.

Also, it would be my contention that direct service mental health professionals are perhaps the most neglected group of all. What difference, if any, has consumer and survivor participation made in their practice activities? What is the effect of mental health reform in general, given the tensions that have arisen over job security? These sorts of questions seem extremely important given that these are the people that the system relies upon to implement, in a practical sense, mental health reform plans. They also represent perhaps the most important power contract there is. The professional-patient/client relationship is where help does, or does not, happen, and, as such, this micro power dyad constitutes a critical focus for continued research.

Finally, some respondents state that they are having the time of their lives because they have discovered their purpose in life. These sorts of statements represent the apparently restorative nature of their activism, indicating that finding a place to belong, a cause to believe in and fellow warriors among whom defeats can be mourned and victories celebrated produces health and well being. Clearly, such positive effects merit further investigation.

In conclusion

The field of mental health has effectively resisted reform for over two centuries, creating over and over again, conditions under which nothing changes and no one gets better. The reality is that the mental health system is both the creation and the creator of the same forces that govern the society in which it is embedded. However, presently, society itself is changing. Toffler (1980; 1990) argues that traditional power relationships are re-forming themselves in response to an explosion in both the amount and availability of knowledge. As the powerful lose their exclusive grip on the production and distribution of knowledge, an opening is created for substantial, world-wide change. In addition, Gil (1996) believes that the long term path to altering what he views as our inherently violent society is the support and nurturance of non-violent liberation movements such as the one consumers and survivors are struggling to create. The goal of this new type of social movement is the emancipation of both the powerful and the powerless through the production and maintenance of new relationships based on empowerment and liberation. Friere (1970) states that oppression, "although a concrete historical fact, is not a given destiny" (as quoted in Duerr, 1996, p. 14). In other words, when initiating social violence is resisted through non-violent protest, the spiral is broken. Indeed, study respondents state that they have found a healthy outlet for their anger. In doing so, they have begun a journey that can only benefit us all. Hugh Tapping asks, "Stronger people, weaker institutions, isn't that the point?" Yes, I believe it is.

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APPENDIX I

INTERVIEW QUESTIONS

Version I, December, 1993

1. Do you think what is currently happening among consumers and psychiatric survivors constitutes a "social movement?" (like the women's, peace, environmental, for example)

2. What led to your becoming involved?

3. Would you call yourself a consumer or a survivor?

4. What do you think mental illness is?

5. What do you think got you involved in the "system" in the first place?

6. What did you expect when you first entered the "system?"

7. What did you get?

8. What does mental health reform mean to you?

9. What does your activism give to you?

10 What does your activism take from you?

11. Do you think Putting People First will make a real difference for consumers and survivors?

12. What do you think the future holds for consumer and survivor activism?

INTERVIEW QUESTIONS

Version II, April, 1994

1. Do you think what is currently happening among consumers and psychiatric survivors constitutes a "social movement?" (like the women's, peace, environmental, for example)

2. What led to your becoming involved?

3. Would you call yourself a consumer or a survivor?

4. What do you think mental illness is?

5. What do you think got you involved in the "system" in the first place?

6. What did you expect and what did you get?

7. What were your hopes for Putting People First before its release?

8. The government speaks of a "partnership" with consumers and survivors. What do you think is meant by this? What is your definition of a partnership?

9. What are your hopes for mental health reform now?

10. How do you decide what to say when you represent the movement? Does the movement speak for you?

11. What does your activism give to you? What does it take from you?

12. What do you think the future holds for consumer and survivor activism?

INTERVIEW QUESTIONS

Version III, November, 1995

1. Do you think what is currently happening among consumers and psychiatric survivors constitutes a "social movement?" (like the women's, peace, environmental, for example)

2. What led to your becoming involved?

3. Would you call yourself a consumer or a survivor?

4. What do you think mental illness is? What do you think should be done about It?

5. What do you think got you involved in the "system" in the first place? What did you expect and what did you get?

6. What are your hopes for mental health reform?

7. What are your hopes and fears for CSDI?

8. By what process did you develop a political framework for your experience?

9. What does your activism give to you? What does it take from you?

10. What do you think the future holds for consumer and survivor activism?

11. How long do you think you're going to stay and contribute?

APPENDIX II

Personal information for the purpose of introducing your comments in the dissertation:

Name: ______________________

Age: ______________________

Approximate date of first incarceration in a psychiatric facility: ____________________

Number of days/month/years spent in a psychiatric facility: ____________________

Your diagnosis: ____________________

Your occupation/work: ________________________________

____

Married/divorced/single: ________________________________

____

Consumer/survivor organization to which you belong (if any): ____________________________

A few words about you: ____________________________

____

____

____

Phone number: ________________

Address: ________________

____

____

RELEASE

I AGREE TO ALLOW MY TAPED AND TRANSCRIBED COMMENTS, IN WHOLE OR IN PART, TO BE QUOTED IN BARBARA EVERETT'S PH. D. DISSERTATION AND ANY PUBLICATIONS THAT MAY RESULT.

I GIVE PERMISSION TO USE (in her dissertation and publications):

MY FULL NAME _____

MY FIRST NAME ONLY _____

A PSEUDONYM _____

I DO NOT WISHED TO BE NAMED AT ALL _____

I WISH A COPY OF THE TRANSCRIPT OF OUR INTERVIEW _____

____________________ ____________________

Witness Participant

____

Date